

**SHIFTING PICTURES IN A KALEIDOSCOPIC WORLD:
CONCERNS OF PARENTS OF PRESCHOOL CHILDREN WITH
DISABILITIES**

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The intent of this dissertation was to move toward a constructive grounded theory that portrayed the ways in which parents of preschool children with disabilities make meaning of their children's social relationships. The rationale for this inquiry emerged from the confluence of four complex discourses: typical child development discourses with particular attention paid to the importance of social development; family discourses with particular attention paid to the role of the family in a child's social development; disability discourses with particular attention paid to the unique challenges families face in supporting the social development of their children with disabilities; and early childhood special education discourses related to family-centered approaches to educational intervention.

Narrative vignettes were used to present the ground of the study. These vignettes were generated from conversational interviews with parents of preschool children with disabilities. Emerging meanings were constructed using a number of conventions of grounded theory analysis and include four conceptual categories: choosing your own reality, holding onto hope, striving to make connections, and struggling for recognition. Additionally, the core concept of living with "shifting pictures" in a kaleidoscopic world

is discussed. This kaleidoscope metaphor is utilized as parents seem to struggle to find a place of belonging for their children represented by symmetry, while simultaneously struggling to avoid social isolation represented by asymmetry.

However, as the research process moved toward culmination a variety of issues began to surface including a narrative shift from the more specific understanding of social relationships to an understanding of the myriad of concerns families face when parenting a preschool child with a disability. These concerns are discussed along with a critique of my use of interpretative grounded theory methods. Implications for practice include the reframing of normal, and the use of empathetic witnessing and reflection as core concepts of early intervention pre-service training and practice. Possible directions for future study may be the effects of HIPAA (the Health Insurance Portability and Accountability Act) and FERPA (The Family Educational Rights and Privacy Act) on the social relationships of children with disabilities, and an exploration of what sense of belonging parents may or may not have for their children with disabilities.

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Sir David Brewster's Toy

In this tube you see
At the far end
A strew of colored-glass debris-

Which, however, grows
Upon reflection to
An intricate pied rose,

Flushed with sun,
That might, set in some cathedral's wall,
Paraphrase the light.

Now, at the least shake,
The many colors jumble
And abruptly make

The rose rearrange,
Adding to form and splendor
The release of change.

Rattle it afresh
And see its coruscating flinders
Quickly mesh,

Fashioning once more
A fine six fold gaudiness
Never seen before.

Many prophets claim
That Heaven's joys,
Though endless, are not twice the same;

This kaleidoscope
Can, in that connection, give
Exercise in hope.

By Richard Wilbur
1987 Poet Laureate

Chapter 1: The Viewing Tube Introduction to the Study

Chapter Purpose and Organization

The intent of this study was to utilize a constructive grounded theory method in order to examine the experiences of parents who have preschool children with disabilities. The insights gleaned from information provided by these parents have allowed me to move toward a substantive grounded theory about the meanings parents make of their parenting experience through discussions about their children's social relationships. I use the term "move toward" for a variety of reasons.

Initially as I began to collect interview text I utilized the term "move toward" as part of an assumption that through the process of dissertation research I would be unable to formulate a complete substantive constructive grounded theory, in part due to limited resources of time and money. Additionally, I assumed as a novice researcher that in the end I would not be able to claim my theory as a "complete" substantive theory if such a thing exists. Assuming that new information and understandings happen constantly the claiming of a complete theory seemed to me a bit bold. Additionally, as Charmaz (2006) has discussed, gathering enough data to fit the task is a practical option for researchers using grounded theory methods. In other words, the claims that could be supported by data or text from a large grant-funded study might be more definitive than the claims made from a smaller scale doctoral dissertation.

Indeed, these ideas did seem to hold true. However, as I moved forward with the study and in retrospect upon completion of the study other major issues with my use of constructive grounded theory also seem to warrant the use of the phrase "moving toward." These issues will be dealt with in Chapter Three in the hope that others coming from a more post-positivist field

may gain some understanding in the use of this methodology by examining my successes and mistakes. In the remainder of chapter one, I provide a brief explanation of personal and professional experiences that brought me to this study. A description of the study follows that includes the intent and guiding questions of the study. The chapter concludes with an outline of the dissertation.

Background to the Study

Personal Experience

I have been asked many times why I wanted to become a special education teacher. The easy answer, and part of the truth I am sure, is that both of my parents were teachers, so the profession was one that was both noble and familiar to me. However, another part of the truth is more difficult to discern. American by birth, I was raised in a decidedly Eastern European culture, and always felt I was somewhat of an outsider to American life. Both of my parents are of Serbian descent as is my entire extended family. I grew up listening to a language other than English, eating foods, adhering to customs, and celebrating holidays that were quite foreign and exotic to my friends. In the home of my childhood we listened to Serbian music and danced Serbian dances. As an adult that frame of reference still makes up a large part of my comfort zone. I revert to the sounds, smells and sights of my ancestors to help me to gain clarity when I am upset or off-balance. My upbringing has afforded me a small glimpse into what it is like to be different. A portion of those experiences led me down the path of special education.

Working as a special educator for the past two decades has provided me with a wealth of experiences and many wonderful opportunities to meet and work with a variety of families. The families I have worked with have discussed a plethora of issues. Many of these discussions have been very individualized (“Can you help me to find out if any hospitals in the United States have

successfully done bone marrow transplants on a young child with Down's syndrome?). Other issues, including children's social relationships, have been more common.

Not surprisingly, each family had its own specific concerns about social relationships. These concerns ran the gamut from sacrificing attention on social relationships, to more basic fears that their child will be excluded and friendless because of their disability. Although the concerns may be different, most families I have encountered have thoughts and opinions on the social relationships of their preschool children with disabilities. Yet, in the hectic pace of daily practice, I often have little time to explore parents' concerns in any depth. This study has afforded me the opportunity to enter into more in-depth conversations so that I might better understand the nuances of parental experiences in supporting the social development of their children.

Professional Experience as an Early Intervention Teacher

As an early intervention (EI) teacher, one of my main responsibilities has been to support preschool children with disabilities and their families in a variety of ways. According to accepted policies and practices from both federal and state agencies regarding early intervention, the six developmental domains of the preschool years include: fine and gross motor skills, cognitive skills, speech and language skills, self-help skills and social emotional skills. Under the initial mandate of PL 94-142, the Education of All Handicapped Children, in 1975, which has been reauthorized (1990; 2004) and amended (1997) as IDEA or the Individuals with Disabilities Education Act, the federal government has provided a broad description for eligibility of early intervention services based in part on these six developmental domains.

However, each state has discretion in determining who will be entitled to services. For example, in the state of New York (www.health.state.ny.us) a child must be delayed by 33% in

one area of development or by 25% in two areas of development to receive early intervention services. In Pennsylvania (www.elc-pa.org) a child is defined as eligible for services if he or she is 25% or more behind peers in one or more developmental areas. A child's score on a standardized developmental assessment determines these areas of delay.

Based in part on these standardized scores the child's strengths and needs are then formulated into an Individualized Educational Plan (IEP) that specifies which professional will address each need, and the location and duration of the services. The IEP serves as a guide to instruction for the school year. Often skill areas overlap and an interdisciplinary team works to provide the support that each child needs, but ultimate responsibility is often divided among several professions. As a result, occupational therapists address fine motor and self help skills; physical therapists address gross motor skills; speech pathologists address communication skills, and teachers address cognitive and social emotional skills. Therefore, as an early childhood educator, one of my main concerns for students has been to help them to develop and improve their cognitive and social emotional skills.

Professional Responsibility to Support the Social Development of Preschool Children with Disabilities

In April 2005 the federal Office of Special Education Programs (OSEP) announced three new reporting requirements for preschool children with disabilities. One of these requirements is that state early intervention programs must now track and report the percentage of preschool children with Individual Education Plans (IEPs) who demonstrate positive social emotional skills (including social relationships). The other two reporting requirements are the acquisition and appropriate use of knowledge and skills, and children's use of appropriate behaviors to meet their needs. According to the National Early Childhood Technical Assistance Center (www.nectac.org) these three areas were included in new policy determining how state programs

report annual performance, because various stakeholders expressed apprehension that separating children's development into separate domains is inconsistent with the integrated nature of how young children develop.

OSEP's recognition of the importance of social relationships for preschool children with disabilities is congruent with the views of many scholars in the field of early intervention who have long discussed the importance of both the social skills and social relationships of preschool children with disabilities (Guralnick, 1990; Guralnick & Neville, 1997; Hall & McGregor, 2000; Hartup, 1979; McConnell, Sisson, Cort, & Strain, 1991). However, the social-emotional developmental domain encompasses such a wide range of capacities and skills that it is often difficult to assess a child's needs and offer appropriate support. For example, the Battelle Developmental Inventory authored by Newborg, Stock, Wnek, Guidubaldi, & Svinicki (1994) is an assessment instrument commonly used with preschool children. The social-emotional domain of this assessment includes child-adult interaction, expression of feelings and affect, self-concept, peer interaction, coping, and social roles.

Other social capacities may include attachment (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1982); information processing, emotions, and the connections between the two (Guralnick & Neville, 1997); entering play; engaging in symbolic play (Guralnick & Groom, 1985); initiating play with peers; and forming and maintaining friendships with peers (Hartup, 1975). Given the scope of social relationship issues that might potentially be addressed by an early childhood educator working with preschool children with disabilities, it is likely that what matters to some parents may not matter as much to others. Therefore, in developing and following an IEP, it is important to understand what meanings parents might ascribe to their preschool children's social relationships.

Professional Adherence to Family-Centered Practices

A number of scholars have suggested that family-centered practices (Bruder, 2000; Wehman, 1998; Woods & McCormick, 2002) and family-professional partnerships (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Chambers & Childre, 2005) are a prime characteristic of quality services. The amendments to the Individuals with Disabilities Education Act (1997) enhanced the essential rights of families of children with disabilities to be involved in their children's education. There is a general consensus within the field of Early Intervention that using effective family-centered practices include viewing parents as partners, providing supports to families, and working to allow families to be integral decision makers in their children's educational plans (Dunst, 2002; Moore, 2000; Murray & Mandell, 2006).

Despite this emphasis on parental involvement, some researchers (Murray & Mandell, 2006) have discussed how teachers have expressed concerns that first-level administrators are not supportive of family-centered practices; and first-level administrators have indicated that second-level administrators neither understand nor support the use of family-centered practices. Additionally, others (e.g., Dinnebeil & Rule, 1994; Dunst, 2000) have suggested that some service providers do not value family-centered service delivery and may lack the skills necessary to support effective collaboration between professionals and parents. Furthermore, as reported by Gettinger, Goetz, Stoiber, and Caspe (1999) parents have expressed similar concerns and have commented that professionals are either unprepared or unwilling to meet their children's or family's needs. If we assume that professionals are more likely to be unprepared than unwilling to meet family's needs, then what might be learned if we explore the ways in which parents think about their children's social relationships? This question gave rise to the study reported in this dissertation.

The meanings parents make of their children's friendships and social relationships have been a consistent interest and concern to me for the past two decades of teaching. As a novice teacher I found it difficult to successfully address the social goals of children with disabilities. This difficulty has not seemed to ease even as my teaching experience and knowledge about child development has grown. This dissertation represents an opportunity to gain a deeper understanding of social relationships, which scholars in the field of early childhood education (Hartup, 1996), early childhood special education (Guralnick & Neville, 1997), and parents (as reported by Hamre-Nietupski, Nietupski & Strathe, 1992) deem to be crucial to children's development.

The Study

Statement of Intent and Guiding Questions

Given the considerations outlined above, the intent of this constructive grounded theory inquiry was to explore and portray the meanings that parents make of their children's social relationships and to draw from this portrayal implications for the practice of early childhood special education. The following five questions serve as a framework for representing the study:

- What is the rationale, and why is it important, for early intervention practitioners to understand the meanings parents of children with disabilities make of social relationships?
- What do I mean by a constructive grounded theory inquiry and what research procedures were used to conduct the study?
- What is the ground of parental meanings from which I am theorizing?
- What theory conveys my understanding of the meanings that parents make of their preschool children's social relationships when their child has a developmental disability?
- What implications can be drawn from this theory for the practice of Early Childhood Special Education?

Organization of the Dissertation

The remainder of this dissertation document is organized into five chapters, each of which addresses one or a portion of one of the guiding questions stated above. Additionally, each chapter title includes a word or phrase that corresponds to a part or parts of a working kaleidoscope. This kaleidoscope metaphor is utilized throughout the dissertation to represent the core concept of my grounded theory, which is *living with shifting pictures in a kaleidoscopic world*. This core concept is introduced in chapter four, and explicated further in chapter five.

In Chapter two, I discuss why it is important for early intervention practitioners to understand the meanings parents of children with disabilities make of their children's social relationships. This rationale is constructed through a review of selected literature drawn from relevant discourses. These discourses represent the lens through which I approached the study.

Chapter three provides information on constructive grounded theory inquiry and the specific procedures I used to carry out the study. To me chapter three represents the “nuts and bolts” of the study; referred to in the chapter title as “the brass and wood tubing” that holds the kaleidoscope together. Additionally, this chapter presents a critique of my use of grounded theory method.

Chapter four, the dichroic glass, offers the portrayal of the ground through the experiential text (Garman, 2006). Dichroic glass is a type of glass that contains multiple thin layers of coated metal on its surface, these multiple layers of metal help to make the patterns in the kaleidoscope more brilliant. Therefore, in chapter four I present narrative vignettes that have helped me to flush out the concepts that eventually became the building blocks of theory (Glaser & Strauss, 1967; Charmaz, 2006). Additionally, within chapter four I offer a series of five vignettes that begin to explicate my core concept of *living with shifting pictures in a*

kaleidoscopic world. This chapter begins to outline the complexity of my core concept, which is further developed in chapter five.

In Chapter five, the object box, I portray the beginnings of a constructive, substantive grounded theory. The object box is central to the workings of the kaleidoscope as it houses the gems and colored stones, but also provides the space for the gems and stones to move around within its borders. My core concept is presented in richer detail as a continuation of the discussion introduced in Chapter four. I explicate my theory by conveying my understanding of the meanings that parents make of their preschool children's social relationships when their child has a developmental disability.

The dissertation concludes with Chapter six, the imagine wheel, which provides a discussion of the implications of my substantive grounded theory for the consideration of other early intervention professionals. To me the imagine wheel represents all that could be. In addition, I offer a personal reflection on my journey from technical to deliberative practitioner.

Chapter 2: The Lens Rationale for the Study

Chapter Purpose and Organization

This chapter addresses the first guiding question of the study: what is the rationale, and why is it important, for early intervention practitioners to understand the meanings parents of children with disabilities make of social relationships? Given that the original intent of the study was to gain a deeper personal understanding of the meanings parents make of their children's social relationships the view through the lens is dominated by early childhood and special education social relationship literature. As my view slowly shifted I drew on literature from other fields, which is included in subsequent chapters. However, drawing initially from selected early childhood and special education literature, I developed a four-pronged rationale for my study.

The first prong of the rationale addresses the generally accepted view that the social development of young children is particularly important. The second prong discusses how families contribute to the social development of their children in a variety of ways. For typical children, adults generally coach them in skills, monitor their play, and step in when necessary in order to teach them how to positively interact with others to form friendships (Thompson, Grace & Cohen, 2001). Consequently, the role of parents, particularly mothers, in fostering friendship opportunities for their typical preschool children has received considerable attention by early childhood researchers.

Utilizing a framework of typical development is common when teaching social skills, among other skills, to children with special needs. This is evidenced by the use of standardized tests emphasizing what skills "typical" children are doing and at what age ranges; and by goals and objectives written on IEP's emphasizing attempts to move children toward skill levels that

are considered to be “within normal limits.” Maintaining age appropriate skill levels for a predetermined period of time is often the hallmark of a child having successfully completed an early intervention program. This ability to achieve and maintain age appropriate skills indicates that a child is no longer eligible for specialized services. As a result, I will offer information on typical social development, and the role parents of typical children play in fostering social relationships. This will provide a backdrop from which to consider the challenges parents of children with disabilities face when attempting to support the social development of their children.

Against this backdrop of “normal development,” I turn to the literature on children with disabilities for the third prong of my rationale. This body of research suggests that families of children with disabilities face many unique challenges, including difficulties supporting the social development of their children. It is here that my interest in parental meanings intersects with my professional role, for as an early intervention practitioner one of my responsibilities is to support parental efforts to help children with disabilities develop socially. Although many of the existing studies focus on school-age children with disabilities, these studies are pertinent as they provide information about relationships as children with disabilities move into broader social spheres.

The fourth prong of the rationale addresses family-centered practices. If, as the early intervention literature suggests, practitioners should take a family-centered approach, then it would be useful to understand what meanings parents’ ascribe to the social development of their children with disabilities. A small but insightful body of literature offers a useful starting point for discussion and understanding of parental meanings of social development for their children with disabilities. It is to this body of literature that this study contributes most directly.

Following this four-pronged rationale I offer a brief selection of literature from the field of pediatric nursing. Within the field of special education qualitative research has often leaned toward positivist results and understandings. My purpose in offering a brief selection of literature from the field of pediatric nursing is to demonstrate the types of understandings that may be gleaned from utilizing more interpretive modes of inquiry, including a constructive grounded theory method. Chapter two culminates with a discussion on why a constructive grounded theory method seems useful for putting diverse meanings into a theoretical perspective that might benefit the field of early intervention.

At this juncture, I would like to clarify my use of the words, friendship and relationship. Within the research literature on social development, relationships and friendships are typically understood to be two different concepts. Friendships are but one aspect of social relationships, and are often described as equal, reciprocal relationships between similar aged peers who are not siblings (Hartup & Sancilio, 1986; Turnbull, Pereira, Blue-Banning, 1999). However, the parents I interviewed discussed a variety of relationships that they seemed to feel provided their children with disabilities the benefits of friendship even though many of these relationships would not qualify as a “friendship” according to research definitions. Some of these relationships included sibling relationships, relationships with older or younger peers, and relationships with friends of older siblings. Therefore, for purposes of this paper I have chosen to utilize the terms friendships and relationships interchangeably.

Social Development and the Typical Preschool Child

Bonding and attachment in infancy set the stage for later social interaction and communication (Woolf, Shane & Kenna, 2001). As the months pass babies increase their social skills by cooing, babbling, and raising their arms to be picked up (Woolf, Shane & Kenna, 2001).

Behaviors that begin in infancy such as eye contact, understanding that people exist even when they can't be seen (known as "person permanence"), and the realization that some people are more important than others all begin and develop before a child's first birthday.

In a recent interview, Dr. Kenneth Rubin (accessed online February 15, 2007 at www.parentsjournal.com/realaudio/kennethrubin-2.ram), who has studied social development and friendship for twenty-five years, stated that during the toddler years children begin to be attracted to and interact independently with other children. Although they do not yet play, they are beginning to learn to take turns and to understand the reciprocal nature of communication. By the age of three children begin to desire contact with other children, they start to play cooperatively, and realize they can communicate to get their needs met by others (Woolf, Shane, & Kenna, 2001). These early understandings set the stage for developing future social relationships.

Rubin (2007) states that by the age of four children have made large leaps in their understanding of and participation in social relationships. They begin to develop a "theory of mind" which is an understanding that others have different emotions and thoughts than themselves. Their use of symbolic representations grows as evidenced by their language skills and imaginary play skills. They are also beginning to be able to empathize with others. According to Rubin, by their preschool years, children are "very complicated beings."

The Importance of Social Development

Rubin also discussed how for typical children the infant, toddler and preschool years are especially important for building later relationships. As Rubin (2007) commented, we are social beings with a need to establish human connections. Snell and Janney (2000) concur stating that the importance of social relationships appears to be self-evident as "social relationships give life

meaning” (p. 3), and seem to have a great effect on our general attitude toward our life and self-worth.

Having friends and other social relationships during childhood seems to set some of the groundwork for later adult relationships (Borba, 2005; Guralnick, 1999). According to Borba (2005), friends help children to “navigate the rough waters of social development” (p. 6), and lead the way for children to learn selflessness, trust, loyalty, intimacy and love. Borba also states that friends help us to learn, among other things, to resolve conflict, to distinguish between right and wrong, to stand up for what we believe in, and to be resilient.

Other researchers (Hartup, 1992; Hartup & Sancilio 1986) agree that friendships and relationships are important and have speculated that the purposes of friendship are four fold: to provide emotional support, to provide a context to practice social skills, to provide a prototype for later relationships, and to provide knowledge that assists in understanding oneself and others. Some social development theorists (Erikson, 1963, 1968; Sullivan, 1953) believe that these early relationships are a necessary step in forming one’s self-identity. In recent years more attention has been given to the study of friendships due to the general presumption by researchers, direct service professionals and families alike that having friends impacts positively on a number of other developmental outcomes (Asher & Renshaw, 1981).

Data from a variety of studies have supported the idea that improvements in social skills may encourage corresponding improvements in children’s other developmental domains, mainly cognitive skills and communication skills (Hartup, 1983; Howes, 1988; Rubin & Lollis, 1988). In addition to teaching children a wide variety of skills and concepts, it is also important to remember that friendships matter to children (Borba, 2005; Dunn, 2004; Thompson, Grace & Cohen, 2001). Furthermore, a child who has at least one good friend seems to be protected to a

degree from traumatic childhood social situations (Thompson, Grace & Cohen, 2001) such as teasing and social rejection.

In contrast, children without friends may be at a greater risk for later “mental health problems, juvenile delinquency, depression, anxiety, failed marriages, and poor job performances” (Borba, 2005, p. 6). Moreover, social skill deficits in the preschool years have been associated with ongoing social problems (Hartup, 1983), such as maladjustment, loneliness and lower levels of achievement (Ladd, Kochenderfer & Coleman, 1996).

Indeed, the development of social relationships seems to matter a great deal to scholars, practitioners, children, and families alike. Few issues seem to cause parents more grief than the possibility that their child may go through life friendless (Doll, 1993; Thompson, Grace & Cohen, 2001). In a study completed by Kennedy (1992) in which he surveyed parents of fifty-two typical preschool children aged three to five, social skills were highly valued. One hundred percent of the parents in this study deemed getting along with others more important for their children than academics or athletics. It seems we can conclude that friendships are a developmental advantage (Hartup, 1992; Hartup & Sancilio, 1986) and an important component to our lives as human beings. Furthermore, families seem to play a pivotal role in helping children to develop socially.

The Context of Family in Children's Social Development

Early diverse studies in the field of child development established the idea that parents and families have a direct and lasting impact on a child's social development. For example, Thomas, Chess and Birch (1968), and later, Thomas and Chess (1977) discussed how a child's temperament has an impact on how the child bonds with his or her mother, and how this early mother-child relationship helps to set the stage for future relationships. Bowlby and Ainsworth

(1965) and Ainsworth, Blehar, Waters and Wall (1978), through the “strange situation scenario,” examined how a child’s attachment to the mother affects his or her ability to venture out and explore the world. Bronfenbrenner (1979) conceptualized an ecosystem model of development typically represented by a series of five concentric circles, and posited that many different systems, including the family, have an effect on development.

Placing the child in the center circle, Bronfenbrenner delineated four systems, the microsystem, mesosystem, exosystem, and macrosystem. The *microsystem* is defined as the immediate environment in which the child operates and typically includes the family and school. The *mesosystem* is defined as two microsystems interacting, such as cooperation between the home and school environments. The *exosystem* is defined as an environment that the child is not directly involved in, but has an impact on the child nonetheless. An example of an exosystem would be the parent’s education level or workplace. Although the child does not have a direct role in this system, parental income, layoffs, and promotions all affect the child. The fourth system is the *macrosystem*, defined as the larger cultural contexts of society that also have an impact on the child, such as societal values or mass media.

In later renditions of his model, Bronfenbrenner (1981; 1986) added a fifth system entitled the *chronosystem*, defined as the evolution and transition of systems over time. One of the important contributions of Bronfenbrenner’s theory was that it shifted attention from a cause and effect relationship of development to one emphasizing the relatedness of each person in context. It helps to understand the uniqueness of each person’s environment and how the interactions between and among contexts and environments have an affect on individual development (Berns, 1997). Lang (2005) suggests that before Bronfenbrenner psychologists studied the child, sociologists studied the family, and anthropologists studied society, but as a

result of Bronfenbrenner's theoretical model connections were constructed among a variety of disciplines that have helped us to begin to understand what it means to be human.

Current researchers and theorists agree with the idea that families play an important role in a child's social development. In the book, *Best Friends, Worst Enemies: Understanding the Social Lives of Children*, Thompson, Grace and Cohen (2001) state:

Parents *do* matter. They matter profoundly. ...Being securely attached matters. Parents make a huge difference in their children's connections with others, for good or ill. Parents influence what children's peer relationships will be like, and those peer relationships in turn influence the kind of people, and friends, children will become (p. 17, emphasis in original).

According to Vogtle (2000) a critical part of building relationships outside of the family circle begins with learning and practicing social behaviors within the family circle. Because children make huge leaps in social development with regard to peer interactions between the ages of two and five, some researchers have surmised that experience within and through the family must be pertinent in shaping children's social attitudes and skills (Howes, 1988; Mize & Ladd, 1990; Mize, Russell & Pettit, 1998). Complex connections and influences seem to exist between family and peer relationships (Finnie & Russell, 1988; Guralnick, 1997; Guralnick, Neville, Connor & Hammond, 2003; Ladd, 1991; Mahoney & Perales, 2003; Parke & Ladd, 1992; Russell & Finnie, 1990); and the experiences that parents provide for their children seem to have an effect on their children's social development (Guralnick, 1999; Lamb, 1981; Maccoby, 1980; Pullatz, 1987).

Thompson, Grace and Cohen (2001) have stated that parents of typical preschool children generally support peer interactions and relationships for their children in two general ways. First, by providing opportunities for their children to play with others parents provide not only valuable peer social experiences, but also the chance to teach their children specific social skills.

Second, by monitoring the play and social interactions of their children, parents teach by example, by stepping in and modeling appropriate behavior when necessary. These two parental actions provide children with a starting point to hone social skills and move toward social independence.

However, what is less well understood is the role of parents of preschool children with disabilities in fostering friendships and relationships. Therefore, the following section provides a backdrop of how parents of typical children provide support for social relationships. Studies examining how parents of predominantly older children with disabilities provide social opportunities will be presented in a separate section because providing social opportunities for children with disabilities seems to present families with a number of unique challenges.

Providing Opportunities for Social Interaction for Typical Preschool Aged Children

Ladd and Golter (1988) studied the relationship between parents' efforts to initiate social contacts for their typical preschool children and the quality of peer relationships both in and outside of school. Once the data were collected and analyzed, the parents were classified as either high or low initiators. Parents who were described as high initiators, organized at least one peer activity per week, tended to have children who possessed a larger circle of playmates, and had children who had more consistent playmates outside of the school setting. Others (Kennedy, 1992; Krappman, 1986 as cited in Ladd & Hart, 1992) have come to similar conclusions.

Kennedy (1992) collected information from the parents of fifty-two typical preschoolers and observed the preschoolers in their school setting. She established that parents who provided regular free-play activities with peers outside of the school setting had children who were favored as playmates in the school setting. Krappman (1986) completed a study with middle school aged children published in German. He found that children who were able to form

friendships that were closer, more stable, and less difficult had parents who took an active role in arranging opportunities to build peer relationships.

Ladd and Hart (1992) further examined the relationship between parental initiation of informal play and preschool children's competence with peers. They concluded that parents who initiate play dates for their children positively impact three aspects of social competence. First, by arranging play dates, parents provide a context that promotes positive social behavior. By inviting a friend over to play, the parent places their child in the role of "host" and encourages courteous and respectful behavior with their guests. Second, by frequently having peers over to play the parent provides regular contact with a variety of children, insuring a more extensive social network than the networks of children who do not regularly socialize outside of school. Third, by involving their children in initiating and arranging informal play dates, parents provided their children with opportunities to practice skills (such as calling and asking a peer to play, or deciding what activities they might do together) that the children would later need to negotiate play dates on their own. Moreover, the children who participated in play dates outside of preschool exhibited less anxiety in school and were rated "better liked" by their classmates, as measured by observations at the children's preschools and a sociometric nomination procedure.

Pettit, Dodge and Brown (1988) also examined early family experiences and young children's social competence. The researchers found that strong social skills at school as rated by teachers were significantly related to mothers' reports of early direct peer experience. Furthermore, prior peer experience was more directly tied to social competence than other kinds of early family experiences. In other words, children who demonstrated greater socially competent skills in the classroom were more likely to have had opportunities for peer interactions at home prior to or in addition to their preschool experiences.

The results of the above studies seem to support the notion that by providing social opportunities for their typically developing children outside of the family setting mothers seem to positively affect their children's social skills and relationships. In addition to providing opportunities for children to play, mothers also typically monitor social interactions and play dates. How a mother coaches her child in play situations is an important strategy for improving peer social competence, which is generally assumed to lead to friendships and social relationships. A number of studies were found that examined maternal monitoring styles.

Maternal Monitoring Styles

In one such study, Russell and Finnie (1990) recruited preschool children and their mothers from four middle-class Australian schools. The social status of the children (*popular*, sought out by peers as playmates; *rejected*, disruptive or aggressive and less sought out by peers due to behavior; or *neglected*, quiet and left out, or treated indifferently) had been determined earlier by teacher rankings. Each mother and her child were invited to join a small existing play-group of two unfamiliar children who were building with blocks.

Each mother was directed to observe the block play for five minutes in a chair set up close to the activity and then to join in the play only if she felt it was necessary to help her child enter the group. The five-minute period was to be used by the mother to talk to her child and offer ideas, suggestions and comments on how to join into the ongoing play. Each mother's instructions to her child were recorded, transcribed and analyzed.

The results indicated that mothers of popular children were more likely to give group-oriented suggestions to enter the group and successfully participate (e.g., "Why don't you tell the boys with the cars your name and ask if you can play with them."), whereas mothers of neglected and rejected children tended to give specific instructions but did not give any details as to how to

actively enter the play already in progress (e.g., “Ask the little boy his name”; “Look at the train he’s building,”). Furthermore, mothers of the rejected children used their authority to take charge of the play, which was often disruptive of the children’s ongoing play.

These results supported earlier findings of Finnie and Russell (1988) who had examined how typical preschool children’s social status was related to maternal coaching behaviors. The data they collected supported their hypothesis that mothers of high social status children (identified by teachers) demonstrated more behaviors that have been identified in the literature as skillful to group entry such as encouraging cooperation and communication among children.

Within the previously discussed Ladd and Golter (1988) study regarding how mothers provide social opportunities for their typical children, maternal monitoring styles and preschool peer relationships were also examined. Monitoring was defined as parents generally being present and involved (direct) or parents generally not present or involved, but aware of children’s activities (indirect). Parents were interviewed and asked how they monitored play dates that involved their children and their responses were coded in one of three ways: direct, indirect and unmonitored. The children were also observed in their school settings, and sociometric ratings and peer nominations were collected.

The results indicated that a direct monitoring style was predictive of undesirable social consequences in school, such as fewer positive nominations from peers, more negative nominations and below average group-acceptance scores as measured by sociometric ratings. Additionally, children with parents who used direct styles of monitoring their children’s play were seen by their teachers as more hostile toward peers, had fewer positive social nominations and more negative nominations.

In general it seems that using a directive monitoring style may have detrimental effects on a child's social competence and by extension social relationships. However, what are the implications of these results for children with disabilities who generally need more direction and support in order to participate in social activities than their typical peers? In a study utilizing a questionnaire that compared the monitoring practices of mothers of both typical children and children with disabilities, Guralnick, Connor Neville, and Hammond (2002), reported that mothers of children with disabilities were more involved when monitoring their children's activities than the mothers of typical children.

Other findings by Guralnick, Neville, Connor and Hammond (2003) have supported those of Russell and Finnie (1990) and Ladd and Golter (1988). Guralnick and colleagues (2003), in an investigation of multifaceted family factors associated with social competence and children with disabilities, found that mothers who used more controlling socialization strategies had children with lower peer competence skills. However, Guralnick et al. (2003) pointed out that the direction of effect was not assessed in this study. In other words, were the mothers responding to the difficulties of their children with special needs by being more controlling or did the children with special needs have difficulties because their mothers were controlling?

The conclusions reached through the above studies seem to imply that for typical preschool children high levels of directive monitoring do not seem to allow the children the opportunity to practice many of the skills necessary to be socially competent later in life (MacDonald & Parke, 1984). While some degree of direction may be necessary when teaching children how to interact with others, the key may be in knowing when to withdraw. Young preschoolers may benefit from initial direction, but if parents linger too long in structuring play, then children may not be able to adapt to less supervised situations (Kennedy, 1992). However,

for young children with disabilities the conclusions are not as clear. Additionally, providing social opportunities for typically developing children seems to have a positive effect on relationships skills outside of the family setting, but parents of children with disabilities face many unique challenges when trying to support the social development of their children with disabilities.

Unique Challenges for Parents of Children with Disabilities

A review of literature on the social development of children with disabilities suggests at least four challenges faced by parents: providing opportunities for social interaction, environmental barriers, parental stress levels, and linkages between school and home programs.

Providing Opportunities for Social Interaction

In contrast to results (Ladd & Golter, 1988; Ladd & Hart, 1992) for parents of typical preschool children, Guralnick et al. (2002) examined the behaviors of parents of preschool children both with and without disabilities regarding the arranging and monitoring of play dates. Three groups of parents were involved: parents of typical children, parents of children with mild cognitive delays, and parents of children with communication disorders. The data were collected using structured interviews and a questionnaire. Conclusions were drawn illuminating the differences in parental behaviors including: parents of typically developing children arranged play more often than parents of children with disabilities; typically developing children played at home with friends more often than children with disabilities; and mothers of children with disabilities reported that they were more involved in the play of their children than mothers of typical children, yet arranged it less.

In a subsequent study, Guralnick, et al. (2003) also found that the arrangement of play dates by parents of children with mild disabilities did not seem to have a direct effect on

children's peer competence skills. Guralnick and colleagues commented that perhaps arranging play is valuable for typical children, but not as valuable for children with delays unless other positive conditions exist, such as structuring of play by the parents and availability and willingness of appropriate play partners. Snell and Janney (2000) also touched upon the notion of positive conditions. They stated that in order for the social relationships of children with disabilities to thrive in school settings certain conditions should be present. These conditions included social opportunities, positive school atmosphere, social support from peers, and motivation of the individual to interact with others.

A study by Baumringer and Shulman (2003) supported the above findings. Twenty-eight mothers of children with and without autism, ranging in age from eight to seventeen, completed an adapted version of the Early Childhood Friendship Survey (Buysse, 1991). In contrast to the mothers of the typically developing children who generally did not get involved with their children's friendships, all fourteen mothers of children with autism stated that their children's friendships were "highly dependent on their ongoing support" (p. 91). These mothers provided opportunities for their children to meet peers; they helped their children to find appropriate friends; they supported the friendship by physically bringing the children together, and they initiated contact with the friend's parents.

Turnbull, Pereira & Blue-Banning (1999) specifically examined how families of children with disabilities successfully provide social opportunities for their children. Using an in depth interview process, data were collected concerning parental facilitation of friendships between children with disabilities and typical peers. Four families were chosen from a larger sample of eleven Hispanic families because of their very active role in facilitating social opportunities for their children. The four families had a total of five children. The youngest child was seven with

a diagnosis of mental retardation, the middle children were twelve year olds with diagnoses of mental retardation and cerebral palsy, and the oldest participants were nineteen-year old twins, also diagnosed with mental retardation and cerebral palsy.

When Turnbull et al. (1999) began sorting and analyzing their data using grounded theory methods, they realized that their categories fit into Schaffner and Buswell's (1992) existing friendship facilitation framework. This framework provides parents with practical suggestions for friendship facilitation and is comprised of three categories. The first of which is "finding opportunities." Finding opportunities, as defined by Schaffner and Buswell (1992), involves arranging and bringing individuals in the community with and without disabilities together. One family in the Turnbull et al. (1999) study specifically discussed how they created opportunities for their child, Angelica, who is seven and mentally retarded, to interact with others.

Angelica's mother took an active role as an advocate for her daughter and fought for her daughter to be included at school and in other community activities. One of Angelica's siblings explained how her parents advocated for an inclusive education: "They [the school district] tested her and they tested her again, and they wanted her to stay there [in the special school]...but my parents said, 'No.' " According to Angelica's family, her alienation decreased when she was permitted to attend her neighborhood school.

Angelica's family also enrolled her in an after kindergarten lunch program, where parents were invited to join their children for lunch. Angelica's mother attended the lunch program regularly and encouraged Angelica to sit with and get to know one of her classmates, Cindy. Coincidentally, Angelica and Cindy met again at community swimming classes, which strengthened their relationship. A similar situation occurred with a peer she met at school who was also involved in the same Girl Scout troop. These overlapping activities helped Angelica to

forge relationships and find common ground with some of her peers. However, without her mother's consistent support and advocacy Angelica may never have been included in these activities, beginning with inclusion in her neighborhood school, which helped her to forge friendships.

Comparable to the results described above, Geisthardt, Brotherson, and Cook (2002) found through interviewing twenty-six mothers of children with disabilities, that these mothers also attempted to provide opportunities for their children to play with peers. However, according to the mothers in this study the variability of success was wide depending on the attitudes of the peers, and the parents of the peers. One mother commented, "They just don't know how to play with her so I kind of gave that up. ...We just never really pursued it...it's sad though, but kids will be kids" (p. 245). Another shared, "I think the only reason mothers don't ask her over is because they are assuming she's going to require more" (p. 245).

Mothers in this study varied in the amount of importance they placed on assisting or initiating their children's interactions with others. One mother reported that she has never encouraged her child to interact with neighborhood children, because they don't understand him, and they go to different schools. Others were going to try to get to know their neighbors better; one was planning to sign up her daughter for Girl Scouts, and one was fighting to have her child attend the neighborhood school. Although a number of parents who were interviewed reported disappointment with their children's lack of friendships, many did not discuss specific efforts to improve their children's social networks.

Furthermore, one mother talked about her son, who is five years old, and has cerebral palsy and is blind, and the repercussions of his exclusion from his neighborhood school. Unlike

Angelica's positive experience, this boy's mother commented on the negative effect of his exclusion from the neighborhood school:

The neighborhood kids, they don't know him, and he doesn't know them. A couple of them have to come to play with my older child but they ignore him. They kind of walk wide around him. I wanted him in the neighborhood school so that he would know the kids and they would know him. Now he is going to this school clear over on the South side. Those aren't the kids that he would be playing with in the neighborhood (Geisthardt, Brotherson, & Cook, 2002, p. 247).

For parents of children with disabilities, it seems apparent that arranging for their child to play with a peer is not as simple as choosing a friend to invite over and hoping they click. Parents need to be willing to push to have their children included in school, community, and social activities. They often need to stay to support their children socially, and they frequently must contend with negative attitudes of others, and possibly deal with a lack of confidence in their own parental skills. Additionally, some mothers emphasized on the occasions when their children were invited to play at another child's home, they needed to feel comfortable that the parent in charge was willing and able to provide proper supervision, especially for behaviors that are dangerous (Geisthardt, Brotherson, & Cook, 2002). In general, parents of children with disabilities seem to need to be involved in their children's relationships to a larger extent than parents of typical children. In playing this type of supportive role parents of children with disabilities often must contend with environmental barriers.

Environmental Barriers

For some children the environment influences their ability to play with friends. Using grounded theory procedures Geisthardt et al. (2002) concluded that physical space, environmental barriers and safety had an impact on how and where children with disabilities were able to interact with peers. For most children play occurs outside, in a family room, or in the child's bedroom. All of these areas are potentially unsuitable for some children with

disabilities. Some families who participated in the study had safe playrooms that accommodated their children with disabilities and could accommodate other children. For other families, however, their indoor space was very limited due to the size of the home, or other necessary adult/family items filling out most of the area of the room.

Additionally, playing outside may be unsafe for a variety of reasons. For children who have behavioral or cognitive issues, playing outside may pose too wide of an open space without defined boundaries which may cause problems. One mother, talking about her own child, shared, “He scared me to death. He got almost all the way to Quaker Avenue before I caught him. He was just running and he’d stop and turn around and laugh. He just doesn’t understand” (Geisthardt et al., 2002, p. 244). For other children with physical disabilities who require assistance walking or use a wheelchair to get around, uneven playground surfaces can be hazardous to navigate independently. Additionally, stairs can be an issue both inside and outside a home. Children who are unable, for whatever reason, to navigate through their environment independently must rely on the assistance of others, typically parents, or run the risk of not being included in social activities.

Furthermore, the researchers and parents in this study talked about children’s access to toys in other environments (toys not placed at a level where their children could access them), the existence or non-existence of curb cuts, safe sidewalks, traffic, and rural settings making access to friends more difficult for children with disabilities. Given the variety of concerns that parents have discussed, one can imagine that parents of children with disabilities seem to have higher levels of stress when compared to parents of typical children. Parental stress levels can also have an impact on a child’s social relationships.

Parental Stress

Much has been written about parental stress and having a child with a disability (e.g., Byrne & Cunningham, 1985; Crnic, Friedrich, & Greenberg, 1983; Dyson, 1997; Tunali & Power, 1993), but the relationship between parental stress, disability and children's social relationships has been less examined. However, some parents of children with disabilities have talked specifically (Weiner & Sunohara, 1998) about some of their concerns which include: trying to come to terms with the fact that their children did not seem interested in friendships, that their children were depressed due to the lack of friendships, loneliness and its relationship to becoming vulnerable, and worries about the inability to sustain relationships. Weiner and Sunohara found that parents of some children tried to do family activities when their children had no one to play with, in essence attempting to fulfill the role of friends. These concerns seem to contribute directly to parental stress levels.

Guralnick et al. (2003) found that parental stress may play an especially important role in children's friendships. They proposed a model addressing direct family influences on peer social-competence for young children with mild delays. They based their model on data from research with typical children and devised seven familial constructs to comprise the basis of the model. The authors hypothesized that six of these familial constructs would have an effect on each other and all would affect the seventh, which is child social competence. The six constructs were: child risk, social supports, parental stress, parental attitudes, parental arranging of social interactions, and parental controlling of social interactions.

The researchers determined that the higher a parent's stress level, the lower a child's peer competence. Although parental stress is certainly not the sole factor in determining peer social competence, it is likely to have an impact on peer competence (Guralnick et al., 2003). Parents

who have children with disabilities, even mild disabilities, have higher stress levels than parents of typical children (Dyson, 1991). Higher levels of stress can lead to lack of confidence in parenting skills, parental feelings of isolation, and adverse parental health (Guralnick et al., 2003). Stress may also predispose parents to be less likely to arrange play dates and to be more controlling when they do occur (Guralnick et al., 2003). Additionally, the difficulties parents face when trying to help their children with disabilities build and link school and home relationships presents another unique challenge.

Difficulties linking School and Home Relationships

The reasons for lack of friendships for children with disabilities are not fully understood (Guralnick, 1999), and the reasons seem to be very complex. One factor that may contribute to the lack of relationships outside of the school setting (Guralnick, 1997; Stoneman, 1993) is the ways in which we are attempting to link the school and home environment. For typical children school seems to be the primary environment to make friends, for children with disabilities that may not currently be the case. Several studies illuminate the issue.

Panacek and Dunlap (2003) reported that typical children identified school friends as their most important group of friends, but children with special needs identified home friends as most important. When children with Down syndrome were asked to invite another child for a play date (Freeman & Kasari, 2002), about half (48%) of them invited children that they knew through their parents or through the community rather than through school. Siperstein and Bak (1989) found that eighty-one percent of adolescents participating in their study identified a good friend outside of their school setting, but half of those identified were adults, paid service or education workers, or friends of a parent. Furthermore, Byrne, Cunningham and Sloper, (1988) surveyed older children with disabilities and found that fifty-eight percent of the students

reported at least one friend at school, but only seventeen percent played with those friends outside of school.

Information has been gathered regarding preschool aged children's social relationships from the school environment (Guralnick, 1999), and many interventions that have shown improvements in children's social skills have been implemented in school settings. However, these effective interventions (Goldstein, English, Shafer, & Kaczmarek, 1997; Halle, 1985; Hundert & Houghton, 1992; Jenkins et al., 1989; McConnell et al., 1991; Odom & Brown, 1993; Odom et al., 1999; Peterson & McConnell, 1993), have not resulted in the ability of children with disabilities to consistently make friends over time and in a variety of settings (Beelman, Pfungsten & Losel, 1994; Kavale & Forness, 1995; Ogilvy, 1994; Schneider & Blonk, 1998). One issue may be that children with special needs often do not attend their neighborhood schools.

Mothers (Overton & Rausch, 2002) have expressed frustration with the neighborhood school issue, stating that because their children do not attend the local schools they do not know other neighborhood children. Therefore skills practiced and common bonds forged with children at school are difficult to revisit in other settings. Furthermore, on the occasion that their child is invited to a birthday party or other event by a school friend, the friend typically does not live in the same neighborhood, which makes access to potential friends difficult. Additionally, their children were often moved from school to school, making it impossible to build any kind of social network of peers. However, these mothers indicated that their personal efforts directed at helping their children make friends, although frustrating, were better than nothing.

The mothers who participated in the Overton and Rausch (2002) study shared how they did not feel that helping their children to bridge the gap between home and school friendships

was being addressed by the school, although they had asked for help with this issue. Other studies (Bauminger & Shulman, 2003; Byrne et al., 1988; Freeman & Kasari, 2002; Kolb & Hanley-Maxwell, 2003; Panacek & Dunlap, 2003; Siperstein & Bak, 1989) have reached similar conclusions: parents want practitioners in the field of special education to provide them with help and support in thinking about the unique challenges parents face when trying to help their children improve their social development, including linking school and home relationships. Positive peer relationships do seem to happen in inclusive settings where supports are abundant, but those supports are not as well defined or developed in the larger community setting for children with disabilities (Guralnick, 1997). Therefore, large-scale interventions and programs involving school, family and community resources may be needed (Guralnick, 1999; Guralnick & Neville, 1997).

Stoneman (1993) has said, “It is of little value to facilitate interactions in the classroom if children with disabilities spend the rest of their time socially isolated in their homes and neighborhoods” (p. 242). Schneider and Blonk (1998) have asked if it is even reasonable to expect that classroom interventions focused on interaction skills will lead to friendships. No matter how perfectly executed the interventions are, can simply increasing specific interaction skills that are successful at school promote friendships in other arenas? As Keefe, Moore and Duff (2006) have pointed out; many scholars have developed effective techniques, however, “the effectiveness of their measures is viewed through a scholarly lens” (p. xix). Measuring effectiveness within the context of the operating classroom, or family or community setting, would perhaps necessitate a different lens.

Additionally, understanding and supporting positive relationships of young children with disabilities may prove to be very important. A longitudinal study examining the peer

relationships of three boys with moderate to severe disabilities over the course of three years (Hall & McGregor, 2000) found that the friendships children had as five and six year olds were similar to the friendships they had at ten and twelve.

However, supporting successful relationships in general remains an area that both parents and professionals find extremely challenging (Danko & Buysse, 2002; Overton & Rausch, 2002).

In summary, children with disabilities seem to be somewhat socially successful in the school setting when supports are abundant. However, they and their families are apparently less successful in the community and in linking school and home relationships. Currently researchers in the field have focused much of their efforts on school interventions. Given that typical children seem to make the majority of their friends at school this seems to be a logical approach. However, as we talk to older children with disabilities and families of children with disabilities, it may be beneficial to shift some of the focus to both younger children with disabilities and their parents, and to home and community settings.

This section has explored some of the unique challenges parents of children with disabilities face when attempting to improve the social development and social lives of their children. The burden of directing the social lives of children is especially high for mothers of children with disabilities. It seems that if mothers want their children with disabilities to play with peers regularly, the mothers need to take the initiative and arrange it (Bauminger & Shulman, 2003; Geisthardt et al., 2002; Guralnick et al., 2002; Turnbull et al., 1999). Additionally, environmental barriers (Geisthardt et al., 2002), parental stress (Dyson, 1991; Guralnick et al., 2003), and difficulties linking social strategies and relationships (Overton & Rausch, 2002) between school and home are among the many complex factors that impact parents' abilities to help their children socially.

Many of these studies have focused on children with disabilities who are school aged. Although we can assume that many of these challenges may be similar for preschool children with disabilities, it also a fair assumption that some challenges parents face may be unique to the preschool years. Given that the preschool relationships of children with disabilities may be indicative of later relationships (Hall & McGregor, 2000) it seems beneficial to understand some of the complexities of the social relationships of children with disabilities specifically associated with the preschool years.

In addition to understanding the unique challenges parents of children with disabilities face, and the actions parents often take in an attempt to support the social relationships of their children, some researchers have begun to study what parents think about their children's relationships. The information we have on this complicated topic provides us a starting point for thoughtful discussion.

Parental Insights into the Relationships of their Children with Disabilities

Guralnick, Connor, and Hammond (1995) gathered information from parents of 262 preschool children with varying degrees of special needs (e.g., cognitive delay, speech delay, physical disability, and at risk for delay). The information was part of a larger study focusing on parental perspectives of both segregated and inclusive preschool programs. Therefore, families were questioned about a variety of school related topics, including friendship. Mothers completed questionnaires and behavior checklists, and were interviewed on two occasions. Parental opinions did reveal that in both types of school placements parents placed a high priority on social development and friendships.

More than three quarters of the mothers in both groups reported that their children could identify one or more best friends. In contrast to the studies with older children with disabilities,

nearly half of the children in the inclusive preschool settings played with one of their school friends outside of school, as did one third of the children in the segregated settings. However, over fifty percent of the mothers who had children in an inclusive setting did not feel that their children had a sufficient number of friends. Interestingly, the parents of children in segregated settings did not express this concern. This may be due to a number of possibilities. Placement in a segregated setting typically indicates that a child has complex needs. Therefore, one possibility may have been that to these parents although friends were seen as important, other medical and therapeutic issues took precedence over friendships. Both sets of parents felt it was beneficial to have typical peers present who would model appropriate social behaviors. However, they did not necessarily feel that typical preschoolers could assist in significantly improving the specific and complex social skill needs of children with disabilities.

Weiner and Sunohara, (1998) targeted the parents of older children with learning disabilities, and utilized in depth interviews to provide a broader view of parental perceptions of friendships both in and out of the school environment. Thirteen children aged ten to fourteen who met the criteria for a learning disability were interviewed regarding friendships. The children were asked questions about their relationships, such as: Who are your friends? How did you meet? What kinds of things do you like to do together? Four to six weeks after the children were interviewed, the parents were interviewed. Using grounded theory method, the researchers analyzed the texts comparing the child interviews to the parent interviews.

Some discrepancies arose between what the children told the interviewers and what the parents told the interviewers. Although the sixteen mothers (and two fathers) who were interviewed knew all of the peers their children identified as friends, they sometimes disagreed with the friend nomination, claiming there was insufficient contact, or that these “friends”

exploited their children. However, seven of the thirteen children with learning disabilities were identified as having at least one mutual friend, and nine of the parents attributed mutual compatibility to the fact that the relationship stemmed from both children in the friendship having a learning disability. Two parents whose children had typical friends were perplexed as to why children who seemed much more competent and mature than their own children would be their child's friends. These two parents concluded that the typical children viewed these friendships as "accepting," "non-threatening," and "relaxing."

Overton and Rausch (2002) also talked to parents specifically about friendships by conducting three focus groups. The focus groups consisted of eleven mothers of children with disabilities, aged five to eleven. These children met the criteria for special education but were included in general education classes at least part of the day. The children had a variety of diagnoses including attention deficit/hyperactivity disorder, pervasive developmental disorder, autism spectrum disorder, learning disabilities, mild cerebral palsy, and Down syndrome.

Although all of the parents in the focus groups felt that making friends was a high priority for their children, they did not feel confident in their abilities as parents to make this happen. The analysis further revealed that the mothers believed that having friends would positively affect other areas of their children's life such as cognitive and physical development, self-esteem, self-confidence, and happiness. Conversely, these mothers believed that a lack of friends would have a negative effect on their children's lives. The mothers interviewed for this study seemed to share the same perceptions about friendship as parents of typical children and scholars in the field.

These mothers also suggested a continuum of acceptable relationships such as peer acceptance, regular playmates, same-age friends, and having one or more "best" friends. These

mothers wanted their children to be included in typical activities both in and out of school. Mothers felt that it could be determined if their child were being included by the observations of both parents and professionals including watching for: low incidences of peer rejection at school, playing with or near other children on the playground, play dates, and receiving valentines and party invitations. One mother, who participated in a study examining neighborhood friendships (Geisthardt, Brotherson, & Cook, 2002) spoke emotionally about the importance of her daughter being invited to birthday parties:

...one kid invited her to a birthday party and then it seemed like all of the other kids wanted to invite her. All this time she never got invited, and it was kind of sad, why can't anyone think of Cassie? But now she is going, and she knows what birthday parties are. She is so proud to take a present (p. 243).

Kolb and Hanley-Maxwell (2003) also gathered information through focus groups from parents of adolescents, twelve to fourteen years old, with high incidence disabilities. Eleven parents of seven children participated. The group discussed critical skills for social interactions and relationships and recognized that their children lacked some or all of these skills needed to foster social relationships. These parents expressed dissatisfaction that the school curriculum addressed only a small fraction of what was necessary to develop and to maintain relationships, despite having articulated to school officials the need for great emphasis in these areas. Parents in this study agreed that parental involvement and collaboration with teachers and school personnel was vital to successfully teaching their children social skills and to helping their children apply those social skills in community settings.

Through the reading of the selected literature presented here it seems logical to conclude that mothers and fathers of children with disabilities have a variety of ideas and thoughts about their children's relationships. Many parents of preschool children with disabilities who attended both inclusive and segregated schools (Guralnick, et al., 1995) felt that their children could name

a good friend at school, but these parents also felt that attending an inclusive school program was not sufficient in itself to teach and foster friendships. For older children parents discussed the different types of relationships they would consider as acceptable for their children (Overton & Rausch, 2002). Furthermore, there seem to be some discrepancies concerning who children with disabilities name as friends and who their parents would name as evidenced by Weiner and Sunohara (1998). In that study parents discussed how their children with disabilities named acquaintances as friends, paid workers such as baby-sitters as friends, or “friends” who took advantage due to the inequality of the relationship.

Other parents (Kolb & Hanley-Maxwell, 2003; Overton & Rausch, 2002) have shared how they feel that helping their children to make friends is a high priority, but they are unsure how to make that happen. By examining literature on parental insights into the friendships of mainly older children with disabilities I have highlighted some of the issues parents face when attempting to support the social development of their children with disabilities, and some of their thoughts on friendship. However, parents of preschool children with disabilities have not received as much attention.

Given the assumption that the family forms one of the fundamental contexts of social relationships it seems important to understand parental insights of the preschool years. Additionally, early intervention practitioners often provide services within the home setting. In early intervention, there is a long and storied history of practitioners talking to parents and trying to understand what parents want for their children. This long-standing philosophy refers to the practice of family-professional partnerships. By talking to parents and cooperating with parents, practitioners play a key role in supporting parental efforts to help their children. Family-professional partnerships are integral to family-centered practices and both are components of

high-quality programming. Effective family-professional partnerships seem to be an important link in helping both professionals and families in the understanding and support of social relationships for preschool children with disabilities.

Family-Professional Partnerships

Ferguson and Squires (1998) discussed how effective family-professional collaboration includes positive and successful communication between the family and the educational system. Turnbull and Turnbull (1997) noted the importance of building a trusting relationship with family members by positing that when professionals have trusting and respectful relationships with families, they can practically ensure that collaboration and empowerment will be enhanced. By the same token, “when families trust professionals, they create opportunities for all sorts of otherwise unattainable results”(p. 73).

How professionals establish connections with families reflects assumptions about how families operate (Ferguson & Squires, 1998). One of the early models regarding how families operated dealt with family responses to stress. Hill’s ABCX model (1949; 1958) provided a representation that asserted that a family crisis (X) is impacted by an initial stressor (A), the family’s resources for dealing with the stressor (B), and how the family defines the stressor (C).

As the educational field’s understandings of families have evolved, other concepts come into play such as resilience (McCubbin, McCubbin, Thompson, Han & Allen, 1997), as well as the cyclical and cumulative nature of stress (McCubbin & Patterson, 1982). In general, understandings about families have shifted from linear theories to more contextual understandings, such as Bronfenbrenner’s (1979; 1981; 1986) concentric circle model, which have helped us to expand our approaches and deepen our knowledge about families in general and of families who have children with disabilities (Ferguson & Squires, 1998). Furthermore,

some of this new found knowledge has been revealed through family accounts and interpretations regarding what it is like to have a child with a disability (Ferguson & Squires, 1998).

Although family-professional partnerships are a well-established philosophy of any early intervention program, there is a noticeable gap between actual practice and “best” practice according to Chambers & Childre (2005). Many families feel that family-professional collaboration is more “rhetoric than reality,” (Ferguson & Squires, 1998, p. 14). Ferguson and Ferguson (1987) surmised that one reason for the inadequacy of collaborative relationships may be that educators and other professionals tend to view family experiences through a professional rather than a family lens. Often family involvement and collaboration implies participation in programming and meetings that professionals have already designed (Ferguson & Ferguson, 1994; Ferguson & Squires, 1998). Another approach has been to train parents to fulfill professional roles, sometimes teaching parents to approximate the structure and techniques of a classroom program (Allen & Hudd, 1987; Ferguson & Ferguson, 1987; Ferguson & Squires, 1998).

Ferguson and Squires (1998) have commented that if the purpose of family-professional collaboration is to build strong linkages between home and school, then making families an extension of the school setting is not a worthy exercise. One parent discussed how attempting to follow through with activities, in effect becoming her child’s teacher was frustrating and unnatural to her:

The harder I worked, the more he would achieve. And achievement was the name of the game. “Developmental milestones” – how I learned to hate those words. Those were the gold medals for the winners of the “fix it” set. I readily became James’ teacher. His playtime at home became “learning time” – actually *all* his time was

learning time. Any free time we had was to be spent on his therapy or to be spent feeling guilty that we weren't doing his therapy (Turnbull, Blue-Banning, Turbiville, Park, 1999, p. 164).

Attempting to foster family-professional relationships by focusing on school-related tasks does not seem to foster a reciprocity implied by the concept of family-centered intervention. Reciprocal family-professional partnerships occur when families can participate in ways that are attuned with the lives they lead with their children outside of the educational setting. By being attuned to the various contexts of a child's life, as presented in part by Bronfenbrenner (1979; 1981; 1986) early intervention practitioners may be able to move toward more reciprocal partnerships with families.

Brown and colleagues (2001) have commented that one of the ways to understand if social interventions are working in the classroom is to ask early intervention teachers if the strategies improve children's peer interactions and relationships within the classroom? One of the ways to begin to answer this question may be for educators to talk to parents and try to understand what parents think about the social relationships of their young children with disabilities, and what these relationships mean to parents. Ferguson and Squires (1998) have stated:

There is a greater need than ever to understand how the accounts of families match the conceptual developments in research...A need persists for more extended narrative accounts from parents and other family members that capture the full range of details of daily life and family history (p. 24).

Therefore, in order to support parents and help children with disabilities with social development it would be beneficial for educators to understand what relationships mean to parents.

The Meanings Parents Make of Parenting a Child with a Disability

More than a decade ago some scholars (e.g., Doll, 1993; Guralnick et al., 1995) pointed out that collecting information from parents about their children's friendships was an uncommon

research practice (Doll, 1993) resulting in a scant body of literature with specific regard to friendships for preschool children with disabilities (Guralnick et al., 1995). In the intervening years a small body of literature has begun to explore the social lives and friendships of a variety of children with disabilities (Keefe, Moore, & Duff, 2006; Panacek & Dunlap, 2003; Weiner & Sunohara, 1998) and the collected experiences of parents of children with disabilities (Ferguson & Squires, 1998; Fisher, 2006; Geisthardt, Brotherson, & Cook, 2002; Harden, 2005; Kirk, Glendinning & Callery, 2005). There is, however, a value in expanding upon this preliminary base of understanding. One source of additional information comes from the literature in nursing where parental meanings related to having a child with a disability have been explored.

The nursing literature, particularly pediatric nursing, can be useful to the special education profession as both follow similar paths: both are concerned with caring for individuals with a variety of health issues and problems; both find it necessary to take the family into account in order to help the patient or student; and both have roots in the medical model of service delivery, although providing cures or answers is not the basis for either profession. Additionally, many health care articles offered concepts and issues comparable to those informing this study. For example, family-centered practices and family-professional partnerships parallel the nursing concept of family-empowerment (Lindblad, Rasmussen, Sandman, 2005). Discussions of a shift from providing services in the classroom to providing services in natural environments such as daycares, preschools and home settings parallel a shift from hospital-based services to home care health services (Carnevale, Alexander, Davis, Rennick, Troini, 2006). Parental experiences of discussing a child's recent diagnosis during a home visit mirrored parental experiences of receiving a child's initial diagnosis in a medical setting (Kearney & Griffin, 2001).

Given these parallels, in this section, I draw from pediatric nursing literature to provide examples of the kinds of insights that can be reached by examining parental meanings through the use of constructive grounded theory inquiry and similar interpretive qualitative methods. Additionally, according to Charmaz (2006) drawing from multiple disciplinary discourses is a common practice for grounded theorists. Along with studies that have utilized a grounded theory method, I will also present personal narrative accounts from special education written by both parents of children with disabilities and adults with disabilities. My hope is that the meanings gleaned from these studies will present a starting point for conversation concerning the use of more interpretive modes of inquiry, such as constructive grounded theory, in the field of early childhood special education. The meanings elucidated by the variety of articles are too copious to discuss. Therefore, I have decided to present two overarching concepts that are pertinent to this study: the paradox of the parental experience and the weight of the words of others.

The Paradox of the Parental Experience

Western culture, and in particular the culture of the United States, places an elevated importance on material items, beauty, youth, athleticism and intelligence. Kirk, Glendinning and Callery (2005) have discussed the importance of practitioners being aware of assumptions that may impact how we provide support to families. Because of our cultural values, having a child with a disability is assumed to have a negative impact on both the child with the disability and the family to whom the child was born (Kearney & Griffin, 2001). According to Kearney and Griffin, this assumption has driven research for decades evidenced by the plethora of studies on this topic from the 1960s to the present. As practitioners, our values, expectations, and professional choices are frequently fueled by these implicit assumptions (Kearney & Griffin, 2001). Kearney and Griffin further posit that when we work with families of children with

disabilities, we apply these long-held tacit professional assumptions, which may have negative implications for the child and the family.

The idea of long-held professional assumptions having a negative impact on practice surfaced for Kearney during the course of working in community nursing. She felt that the families she worked with, and there were about two hundred who had a child with a disability in her practice, generally seemed to manage their lives “cheerfully and constructively and, although there was pain, they mainly dealt with it” (p. 583). Her experiential knowledge did not seem to be congruent with her theoretical knowledge. One parent, Amanda, seemed to sum up Kearney’s thoughts while discussing the birth of her daughter, Annie:

I knew her condition was serious and her prognosis poor but, to me, she was my firstborn, beautiful child. Every time I expressed my joy to the staff at the hospital, they said, ‘She’s denying reality.’ I understood the reality of my child’s situation but, for me, there was another reality (Kearney & Griffin, p. 583).

This interaction and other interactions with families who Kearney knew through her work in community nursing, led her and her colleagues to complete in-depth interviews with six parents of four children with disabilities.

Drawing on the work of Larson (1998) and the parental experiences that were shared with Kearney and Griffin led to an interpretation by the authors that resulted in a conceptual model depicting the tensions between joy and sorrow. Kearney and Griffin (2001) questioned why professionals seem to often neglect the joy that parents so apparently derive from their children regardless of their disabilities. They posited that perhaps because joy is ambiguous professionals might have a difficult time in understanding and supporting parents within the ambiguity of experience. The task becomes more difficult they posit because parental experiences are often couched in the often-simultaneous paradox of both positive and negative emotions, making it confusing for professionals to determine what should be addressed.

Barnard (1995) has also discussed the “existential paradox of chronic illness” (p. 39). He explained that human beings with chronic illness or disability live suspended on the boundary between finitude and transcendence. In other words, they exist between the finality of their condition and the hope that they may one day be able to go beyond the factual limits of human expectation. Barnard explains how a person with a chronic illness or disability is pulled between two extremes.

In one direction, he may become wholly identified with the impaired self, feeling no access to any part of the self that is independent of impairment...In the opposite direction, the identification is only with the part of the self that is free of impairment (p. 41).

Others (Kappes, 1995; Larson, 1998; Marsh, 1995) have also discussed this paradox in the context of disability. In his book *Uncommon Fathers*, Kappes (1995), who has a son with a disability, has described his emotional fluctuation between extremes, often taking place at the same point in time, “I derive comfort from the thought that it’s the sand grain that seeds the oyster’s pearl” (p. 25). Larson describes parents of children with disabilities as “embracers of paradox” (p. 870). Embracing this paradox has several layers: holding two oppositional thoughts about the child, loving the child as they are and yet wanting to erase the disability, hoping for a more positive future contrary to the opinion of others, and recognizing there is no cure while continuing to hope for a solution. Larson, who interviewed mothers of Mexican origin, spoke with Mariza, the mother of a ten-year-old girl with severe disabilities who said:

Well, the difficult thing is that you always want your child to be normal...That’s the difficult part, because you know in your heart that...you are never going to see that.

Marsh (1995) wrote a narrative about her experiences related to having a daughter with a disability in the book, *From the Heart*. Marsh shares:

Yet while I grieve, I also hold deep love and joy for Jessica, knowing that she is perfect just the way she is. It is such a paradox; I am finally learning to embrace this paradox of joy and grief that I will always hold, rather than telling myself that I shouldn't feel this way.

Understanding this paradoxical nature of parenting a child with a disability seems as if it would strengthen the ability of early intervention practitioners to connect with parents and to provide the kind of information and support they would deem helpful and worthwhile.

Indeed, Rosenbaum, King, Law, King & Evans (1998) have stated that considering parental perspectives may help practitioners to provide services that are more family-centered. Featherstone (1980) has posited that families look to professionals for understanding as well as information and practical help. Moreover, Kearney (2001) has suggested that by listening and trying to understand families' experiences professionals may be able to foster insight and empathy, which may lead to the ability to offer support in more sensitive ways. In addition to examining the paradoxical nature of parenting a child with a disability, Kearney and Griffin also discussed how the words and views of others seemed to greatly affect the families they interviewed.

The Weight of the Words of Others

The parents who participated in the Kearney and Griffin (2001) study viewed their parenting experiences as positive, and felt that most of their sorrow was related to "their dealings with other people's frequent messages of negativity and hopelessness" (p. 586). Kearney and Griffin discussed their surprise that the words of others had such an impact on the sorrow of the families they interviewed. However, Pollner and Stein (1996) have also theorized how interactions with others seem to help individuals to renavigate their experience, either positively

or negatively, and to create “narrative maps.” These maps often continue to function long after formal discharge from the medical, rehabilitation or educational system. The construction of a new map plays a noteworthy role in teaching a person how to be disabled and how to interpret disability (Frank, 1995). Additionally, by listening to the stories and experiences of others we confirm that those stories and experiences are worthwhile (Frank, 1995), and by extension the individual telling them is also worthwhile.

King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2005) interviewed among others, one mother of a child with Down syndrome who seemed to exemplify this idea.

I had the perception at the time that the whole future was laid out in front of me and it was very, very ugly...and it was something that I couldn't do anything about. And for two years I cried whenever I was alone - in the shower, the back yard, public washrooms... And the single most abiding problem was that I thought I was ill-equipped to do this... But I did meet a professional who struck me as very positive... She just said to me one day, “You know there is another way of looking at this.” ...Whenever she spoke about my son, ...she would describe his behavior in a positive way. ...That's when the crying stopped – when I realized that I could re-language it, could rethink this and it would result in a different experience (p. 360).

For this parent it seems that how *one* professional communicated with her helped her to change her outlook for both her own and her son's future. When interacting with families, it appears it would behoove early intervention practitioners to be aware of the weight of our words. Not only when discussing the social relationships of children with disabilities, but in all other realms in which we provide information and support for families. In addition to the families of children with disabilities, adults with disabilities have also reported being strongly influenced by others perceptions (Lutz & Bowers, 2005).

Lutz and Bowers (2005) interviewed seventeen adults with disabilities and analyzed the data using dimensional analysis. Dimensional analysis is very similar to grounded theory and “allows the researcher to identify how individuals carve out reality” (p. 1041). Lutz and Bowers

found that the adults with disabilities who were interviewed expected professionals to understand that disability is but one aspect of their lives, and not a central or solely defining characteristic. However, many adults reported disappointment that this had not been the case.

Lutz and Bowers eventually conjectured that “the influence of others’ views...was more insidious and profound” (p. 1046) than that of other fundamental aspects of disability such as issues related to mobility, cognition, the ability to communicate, energy level, and stamina. In other words, aspects of disability that non-disabled persons would consider to be paramount to the impact of disability on a person’s life seemed to have less of an effect than the perceptions of other people.

Moreover, in addition to the perceptions of others affecting how people with disabilities saw themselves and measured their self-worth, the perceptions of others also had an impact on how people with disabilities were identified and what services they received. Therefore, people received services they did not always feel were necessary, and services that they felt would have a larger impact on their lives were often neglected. Lutz and Bowers (2005) explain, “others’ views determined how the needs of persons with disabilities were identified and how services to address these needs were prioritized...and many participants described difficulties...because health care providers focused on the disabling condition, dismissing a need for other services” (p. 1046).

This short review of selected pediatric nursing literature opens a small window into the types of understandings that can be gleaned from the use of interpretative qualitative research, including constructive grounded theory. It seems that others’ perceptions of disability are more far reaching than initially suspected, and affect a variety of aspects of life that may not have been easily predicted without the experiential knowledge of persons living with a disability.

Moreover, how parents view their child's disability and their experience of parenting a child with a disability may not be congruent with how professionals view this experience. The information presented here was gathered through research methods positioned on the interpretive end of the qualitative research spectrum, and seem to elucidate the idea that what we "know" to be true may only be our perception. Therefore, it seems reasonable to assume that continuing to focus on parental meanings of disability is a worthwhile pursuit.

Why More Study is needed on Parental Meanings of Social Relationships

Although researchers have begun to examine parental meanings of disability, parental meanings of social relationships is a far less common topic. Attempting to understand what parents think about and want in relation to social relationships for their young children with disabilities seems to be important within the concept of family-centered practices and family-professional partnerships. Currently, enhancing social relationships for children with disabilities are driven by the goals and objectives on Individualized Education Plans, which often target the acquisition of specific social skills. This may or may not be a helpful approach for parents, and in a field that strives to be family-centered it seems it would be illuminating to engage in conversations with parents to attempt to understand their experiences.

To summarize, first, it seems clear that social development is an important aspect of child development, and that social development begins within the context of the family. Additionally, parents and families of children with disabilities face unique challenges when attempting to support the social development of their children. As early intervention practitioners we have a professional responsibility to support family-professional partnerships, and we play a key role in supporting parents in their attempts to help their children's social development. Finally, as

evidenced by the studies presented above from the field of pediatric nursing, some of our long-held assumptions about disability may be incorrect.

These assumptions may impact how we effectively collaborate with and support parents and families. An important step in successfully collaborating with families and helping them to support the social relationships of their preschool children with disabilities seems to be understanding what meanings families ascribe to those relationships. Understanding ascribed meanings is primarily studied through interpretive inquiry. Ferguson (1993) defined interpretivism as the belief that facts do not exist waiting to be discovered, but are instead socially constructed by human beings attempting to understand the world in which they live. Therefore, absolute truth or reality do not exist, and any truths or realities that are understood and agreed upon by human beings are constructed by individuals, in conjunction with other factors such as social, political, or cultural mores and values (Mantzoukas, 2004). Ferguson (1993) described this nature of social inquiry as the “interpretation of other people’s interpretations” (p. 36).

By utilizing an interpretative framework we assume that meanings are unique to individuals. Viktor Frankl (1959; 1969; 1988; 2006), a world-renowned psychiatrist, neurologist, and concentration camp survivor shares an analogy regarding interpretation and the individual uniqueness of meaning (2006). He posits that if one were to meet the chess champion of the world and ask, “What is the best chess move?” An answer would not be possible. There is no such thing as the best move or even a good move if you do not understand the context of the game that is being played including previous moves, your own personality, the personality of your opponent, the stakes of each particular game, and so on. For each move, the “best move,” would be different. Therefore, he comments, “one should not search for abstract meaning...one

can only search [for meaning] by *answering for one's own life*" (emphasis in original, p. 109).

Frankl (1988) also states:

The foremost task of education, instead of being satisfied with transmitting traditions and knowledge, is to refine the capacity which allows man to find unique meanings...Man must learn more than ever to listen to the ten thousand commandments arising from the ten thousand unique situations of which his life consists. And to these commandments he must rely on his conscience...In short, we have to make decisions as to what is essential and what is not...One never knows whether or not it is the true meaning to which he is committed. And he will not know it even on his deathbed (pp. 64-65).

A constructive approach to grounded theory (Charmaz, 2006) offers a useful methodological framework for understanding and placing diverse individual meanings into a larger theoretical perspective. Therefore, by attempting to broaden *my* understanding of what meanings families ascribe to the social relationships of their children with disabilities, I hope to enrich my practice in ways that I cannot currently imagine without the input of families. As Nel Noddings (2006) has stated, "Possibly no goal of education is more important- or more neglected - than self-understanding" (p. 10). Noddings looks to Socrates for support with his advice of "know thyself" and his words of admonition that an unexamined life is not worth living. By enriching and sharing my own understandings through constructive grounded theory method I hope to enrich the practice of other early intervention professionals.

Although constructivist and interpretive research is not the norm in special education there is existing discourse in the field (Ferguson, Ferguson & Taylor, 1992; Ferguson, 1993; Giangreco & Taylor, 2003; Heshusius, 1996; Pugach, 2001; Vohs, 1993; Wesley & Buysse, 2001). In 2001, Wesley and Buysse asked if the field of early childhood special education was "ready to move toward accepting the conceptual analyses and interpretive knowledge of practitioners and families as part of a redefined knowledge base, rather than relying on the traditional approach to discovering new knowledge through the scientific method" (p. 122). I

hope to contribute to this dialogue that interpretative ways of knowing, including constructivist grounded theory, are methods with relevance to the field of early childhood special education.

Chapter 3: The Brass and Wood Tubing Procedures of the Study

Chapter Purpose and Organization

This chapter addresses the second guiding research question: What do I mean by a constructive grounded theory inquiry and what research procedures have been used to conduct the study? In describing my procedures, I give particular attention to the following: a description of a constructivist approach to grounded theory, an explanation of the procedures used to select and recruit participants, how interview texts were gathered, a brief discussion of some unforeseen ethical issues I encountered, and the procedures I utilized to construct the experiential texts. The chapter concludes with a discussion focusing on how I moved from the ground of the experiential texts to a more theoretical text, which led to a portrayal toward a substantive grounded theory.

Additionally, as I stated in the introductory chapter of this dissertation I also offer a critique of my use of grounded theory method within chapter three. My struggle to construct a grounded theory at times veered away from common conventions of the method within an interpretive framework. This was due to a variety of factors including my reality of beginning this journey from a post-positivist stance within a post-positivist school of thought. My original literature reviews, potential study outlines, overview and personal understandings of method were more often than not grounded in positivist language and thinking. As I struggled to understand and to blend pieces of the old with pieces of the new, which was moving me toward a more interpretive understanding of grounded theory, I was successful as often as I was unsuccessful. Therefore, this critique, which is embedded throughout this chapter, is offered in the spirit that others may learn from my steps and missteps.

A Description of Constructivist Approach to Grounded Theory Method

Glaser and Strauss' seminal work *The Discovery of Grounded Theory* (1967) proposed an inductive process for generating theory from observations of phenomena as they occur within social contexts. Since Glaser and Strauss' original articulation of grounded theory, discourses about the method have evolved in both post-positive (Glaser & Strauss, 1967; Strauss & Corbin, 1990) and constructive directions (Annells, 1996; Charmaz, 2000; Charmaz, 2006; Piantanida, Tananis, Grubs, 2004; Rennie, 2006). Charmaz, in particular, provides insight into a constructivist approach to grounded theory.

As a graduate student, Charmaz studied with both Glaser and Strauss at the University of California where they encouraged researchers to be flexible and use grounded theory in individualized ways. Exercising this freedom, Charmaz departs from the thinking of her mentors in that Glaser and Strauss talked about discovering theory within the data. In contrast, Charmaz (2006) assumes that "neither data nor theories are discovered. ...Rather, we construct our grounded theories through out past and present involvements and interactions with people, perspectives, and research practices" (p. 10).

Charmaz (2000) describes the intent of constructivist grounded theory as a way to further the researcher's knowledge and understanding of one's own and others' subjective experiences and to represent these experiences in some way. Although approaches to grounded theory differ, similar intents have been offered such as, to gather insights about lived experiences (Piantanida, Tananis, & Grubs, 2004), to offer insight and enhance understanding (Strauss & Corbin, 1994), to study experience (Rennie, 2006), and "to describe the world of the people or peoples under study" (Stern, 1994; p. 213).

In order to further one's own understanding of the experiences of others, grounded theory researchers often use interviews. According to Weiss (1995), "it is impossible to observe the internal events of thoughts and feelings except to whom they occur. Most of the significant events of people's lives can become known to others only through interview" (p. 2). Therefore, in order to gain insights into the meanings parents make of their children's social relationships; I sought out parents to interview. I utilized my understandings of these parental insights to construct the "ground" of the substantive grounded theory.

Recruitment and Selection of Participants

Recruitment Site

To locate parents whose children have disabilities, I turned to the Allegheny Intermediate Unit (AIU). I felt the AIU would be a fruitful site for the recruitment of study participants for several reasons. First, the AIU provides early intervention services for children aged three to five with developmental delays. Therefore, their client population includes the types of parents whose experiences I was most interested in hearing. Second, because the AIU is a countywide program, it provides services in a variety of areas including affluent suburbs and urban neighborhoods. Families of children receiving services also vary in terms of age, marital status, and socioeconomic levels. The range of children's disabilities is also quite broad. Some children have mild speech delays while others have diagnoses such as mental retardation, autism, and cerebral palsy.

Given the diversity of families served, it seemed likely that I would be able to recruit participants with varied parenting experiences. This, as Glaser and Strauss (1967) contend, is an important part of the grounded theory feature of theoretical sampling – i.e., seeking as much diversity of study participants as possible in order to probe differences in the experience being

studied. In order to encourage diversity among the participants the criteria for selection were quite broad and included: having a child between the ages of three and six years old who has been identified as eligible and was receiving early intervention services.

Recruitment Process

As I considered avenues for reaching out to AIU clients and requesting participation in my study, I realized that there were two subgroups of families I might contact – those with whom I had a prior working relationship and those whom I had never met. Parents in each group, I speculated, might have different levels of comfort in sharing their experiences with me. As Charmaz (2000) suggests, building relationships with interview respondents can be an important step in encouraging the sharing of personal stories. Yet, brief encounters with strangers, like those occurring on airplane flights, hold an allure for sharing personal information with someone who will never be seen again. Whether or not a pre-existing professional-client relationship would yield richer interviews than those with strangers remained to be seen. But at the outset of my study, I felt my thinking would be enriched by talking with parents in both groups. The criteria for selection were the same for both sets of parents. However, the process of identifying parents who would be willing to be interviewed followed two different paths.

Recruitment process for former clients. I was employed as a developmental therapist for five years by an agency that provides services for children who are birth to three years of age. While employed, I worked extensively with numerous families, visiting each family on my caseload for an hour once a week. Some families I saw every week for three years, from the time their child was a few weeks old, to the child's third birthday. (When children turn three, if they are still eligible for special education services, they transition to the AIU. Many of the

families I worked with now have children who have transitioned to the preschool programs provided by the AIU.)

Additionally, by involving families I knew I hoped to secure the participation of fathers as well as mothers. Many studies have focused specifically on mothers (Baumringer & Shulman, 2003; Geisthardt et al., 2002; Guralnick et al., 1995; Overton & Rausch, 2002) or mothers have been the majority informants (Buysse, 1993; Doll, 1993; Guralnick et al., 2003; Turnbull et al., 1999; Weiner & Sunohara, 1998). If I were able to interview fathers, I felt this might offer a different perspective, since existing research suggests that fathers relate to their children differently than mothers (Parke, 1996; MacDonald & Parke, 1984; Volling & Belsky, 1992), and that paternal involvement in play has been associated with peer social competence (MacDonald & Parke, 1984).

Moreover, by recruiting participants I knew I thought I might create opportunities to interview other family members who help to care for the children. This inclusion of a variety of family members is in keeping with Trachtenberg and Batshaw's (1997) definition of family and family-centered practices, a central philosophy of early intervention. Therefore, I kept a running list of parents who might be interested. I sent a letter (see Appendix One) to these parents explaining the purpose and voluntary nature of the study, and I asked if they would be willing to be interviewed. The interested parents contacted me by email, phone, or by returning the lower portion of the letter in the self-addressed stamped envelope that I provided. When parents contacted me and agreed to participate, an interview time and location were arranged.

Recruitment process for unknown parents. An administrator at the AIU and I met jointly to develop a strategy for contacting parents with whom I did not have a previous relationship. We agreed to target nine classrooms in both urban and suburban locations in order to provide a

wide variety of possible respondents. The children who attended these classrooms also had diverse disabilities ranging from physical disabilities to mental retardation to autism. The nominating administrator made initial contact by sending letters (see Appendix Two) to the teachers in the identified early intervention classrooms.

The teachers in turn sent letters out to the families (See Appendix Three). A total of 108 letters were sent in the spring semester of the school year. The letters were sent to each student's home from the school in the student's backpack. The letter (see Appendix One) explained the purpose and voluntary nature of the study, and asked if parents would be willing to be interviewed. The interested parents contacted me by email, phone, or by returning the lower portion of the letter in the self-addressed stamped envelope that I provided. When parents contacted me and agreed to participate, an interview time and location were arranged.

Study participants. For purposes of my dissertation, I anticipated that twelve conversational interviews would provide me with enough raw text to begin to theorize and to develop a coherent picture of how parents make meaning of their children's social relationships. I contacted four families with whom I had previously worked and all agreed to be interviewed. Of the 108 families contacted through the schools, I received only five responses. Ultimately I completed nine interviews with eleven people (nine mothers, one father and one grandmother) who are family members to eleven children with disabilities. I had hoped to recruit a diverse population, but the majority of parents who responded were college educated, married, lived in suburban neighborhoods, and were of European descent. At this time there was discussion with several of my committee members regarding the feasibility of recruiting more participants. The likelihood of gaining more participants through a second round of recruitment efforts seemed unlikely. We were concerned that additional contact might seem intrusive and coercive. And at

a practical level, the school year was coming to an end so sending letters through school programs would have had to wait until the start of the following school year, with no guarantee of a higher participant return rate.

I feel it is also important to note that over half of the children whose families I interviewed had a diagnosis on the autism spectrum. Because autism has inherent in its diagnosis difficulties with social issues, it was noteworthy to me that several parents of children with this diagnosis chose to participate. It may have been happenstance, or just as likely, social relationships are a topic of particular interest to families with a child who has any form of autism, which compelled them in some way to participate. Appendix Four provides background information on all of the participants. Additionally, the severity of disability classifications are based on each child's areas of delay gleaned from information the families gave to me. The families may have classified their children as having greater or less degrees of disability than I did.

Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005) have suggested that specifying the number of participants, prior to a qualitative study is not always feasible. This is particularly true in the case of inductive grounded theory studies where the convention of theoretical, rather than statistical, sampling guides the collection of data. Within grounded theory the concept of "saturation" is seen as a hallmark of when to stop collecting data (Charmaz, 2006; Glaser & Strauss, 1967). Charmaz (2006) defines categories as being saturated when "gathering fresh data no longer sparks theoretical insights" (p. 113), differing from other definitions of saturation which imply that the researcher is not hearing any new ideas.

Dey (1999) has questioned the use of the term saturation. If the meaning of each experience is unique to the individual then theoretically one could always hear new information.

Dey views the term saturation as “an unfortunate metaphor” (p. 257) and points out that grounded theorists name categories through partial and not exhaustive coding (Charmaz, 2006; Dey, 1999). Dey contends that researchers arrive at categories that are *suggested* by the data and further posits that the term “theoretical sufficiency” (p. 257) makes more sense for researchers who do grounded theory. Charmaz (2006) seems to agree with Dey’s views by wondering when and if it is ever appropriate to claim true saturation.

Interviewing more families would have more than likely added to the richness and depth of my study and led to greater theoretical sufficiency. However, Charmaz has stated that sufficient data must “fit the task and give as full a picture of the topic as possible within the parameters of the task” (p. 18). Given these considerations, proposing a grounded theory study presents doctoral students with a dilemma. On one hand, committee members are likely to want specific information about the number of individuals to be interviewed in order to be assured that a substantive study will be conducted. On the other hand, following conventions of grounded theory, the researcher is obliged to continue to collect data until reaching theoretical saturations or sufficiency, a point that can’t be determined in advance of the study.

To address this dilemma, I initially proposed conducting twelve interviews with the understanding that I might do more as needed. When I received so few responses to my initial recruitment efforts and decided that another round of recruitment was unlikely to be productive, I turned to the literature for additional information about the experience of parenting a child with a disability. Therefore, I utilized selected passages from interviews that had been published in the research literature. Selected articles and passages were chosen that were pertinent and that supported or illuminated ideas or concepts that I had found particularly compelling.

Had this study been a full-fledged, funded grounded theory project, I realize that I would have been obliged to continue with theoretical sampling and data collection. Within the constraints of an unfunded dissertation, however, extending the data collection efforts was unfeasible. From this perspective, then, the insights I offer about the experiences of parenting a child with a disability represent my efforts to theorize about the specific group I interviewed. In this sense, theoretical saturation or sufficiency means mining as fully as possible the data set I had collected. In other words, the “ground” of my study was limited to the experiences of nine families and the insights I offer in subsequent chapters represent my efforts to put what I learned about their experiences into a conceptual framework that might be helpful to other early intervention specialists.

In all honesty, there is one other point I want to make about the concept of theoretical saturation. Because the dissertation represented my attempt to shift from a post-positivist to a constructivist understanding of research and because I had no prior experience in interpreting interview transcripts, I found it difficult to mine the data for multiple layers of meaning. As one committee member remarked during my defense, “It was you who became saturated!” Looking back, I think this remark accurately describes what occurred when I was faced with a wealth of interview data.

Gathering of Interview Texts through Guided Conversations

In attempting to uphold family-centered practices, I met with participants in whatever location each participant deemed appropriate. Therefore, the majority of families were interviewed in their homes; one mother was interviewed in a local coffee shop, and one mother was interviewed at her place of work. Mostly mothers agreed to be interviewed. However, in one case, both mother and father agreed to participate in the interview, and they chose to be

interviewed together. One other mother included her mother (the child's grandmother) in the interview. This particular grandmother had been an active participant in previous early intervention services for her grandson. All families agreed to face-to-face interviews. On a few occasions follow-up questions were asked via telephone. The initial interviews took on average an hour and a half. Each interview was taped and transcribed by me to create a stable interview text.

I also chose to gather the experiences of parent through conversational interviews (Rubin & Rubin, 1995). Utilizing a conversational approach implied that I was open to having my mind changed and that I hoped to be viewed by the parents as an equal participant in the process. I did not meet with parents *to do* an interview, but to have a conversation *with* them. By engaging in conversations I hoped to dispel the notion that they were subjects "being studied," and hoped instead to provide them with a sense of contributing to a deeper understanding of the issue under study.

Several qualitative researchers in the field of special education agree that in order to collect text in a most productive way, flexibility is key rather than a standardized interview protocol (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005; Ferguson et al., 1992). Therefore, my conversational interviews were guided by overarching objectives (Rubin & Rubin, 1995) rather than a detailed protocol of specific questions. Thus, I gathered information that would help me to understand the following issue: How have parents experienced and made meaning of the social relationships of their preschool children with disabilities?

Evocative prompts (such as "How did you learn that your child has a disability?" or "What has the parenting experience been like for you?") were used to initiate the conversation and to prompt parents to tell their stories. As the conversations continued I utilized probing

questions that built on the comments of the parents. Although the conversations touched on many subjects, I also guided the parents toward a discussion of how they make meaning of their children's social relationships and friendships.

For example, if friendship was mentioned during a conversation about the child's involvement in the neighborhood, I might say, "You mentioned Jay's friend, Michael. I was wondering if you could say more about that?" If, however, friendship did not come up in during the natural course of the conversation I continued with, "I really appreciate having the background information about Jay. What I'd like to talk about now is a topic that comes up frequently in special education. It's the issue of friendships and social relationships. I'm wondering how you think about social relationships and friendships for your child? Do you have any initial thoughts that you could share with me?"

Additionally, I assumed that by choosing what to probe when I interviewed parents, what follow-up questions to ask, and what to focus my writing on, would help me to position myself within my own customs and beliefs to examine and interpret parental experience in congruence with some of Schwandt's (1999) ideas. However, I also tried to remain open to uncertainty and a willingness to challenge my thinking about how parents make meaning of the social relationships of their children. Schwandt (1999), using the work of Gadamer (1989), argues for this relational nature of understanding.

Schwandt (1999) distinguishes among three different relationships that one may draw on to understand another. In the first, attempts to "discover" the typical behavior of the Other are approached without taking one's own understandings into account; understanding of the Other is completely separate and objective from oneself. The second approach entails claiming to know the Other, and indeed often claiming to know what is better for the Other based on one's own

knowledge and experience. The third approach posits that in order to understand the Other, one must understand oneself. It is only through the relationship between one's self and the Other that one is open enough to allow the Other "to say something to us" (p. 458).

Therefore, rather than approaching parents in an uninvolved, "objective" way, I became fully engaged in the interview interactions. This process held transformative possibilities for my understandings of the meanings parents make of their children's development of social relationships. It is this possibility of transformation that created a context for generating implications for the practice of early childhood intervention.

Schwandt (1999) contends that:

... understanding requires an openness to experience, a willingness to engage in a dialogue with that which challenges our self-understanding. To be in a dialogue requires that we listen to the Other and simultaneously risk confusion and uncertainty both about ourselves and about the other person we seek to understand. (p. 458)

Schwandt's view of engagement in conversation offers a bridge to the grounded theory principle of theoretical sensitivity coined by Glaser and Strauss in 1967. In general, theoretical sensitivity refers to what the researcher brings to the study.

Theoretical Sensitivity

Within grounded theory, the researcher's theoretical sensitivity plays a crucial role during the interviews, during coding and analysis, and during the construction of theory. During the interviews, theoretical sensitivity helps to guide the researcher in what to listen for and how to follow important cues during the conversation. Charmaz (2006) describes theoretical sensitivity as the act of examining life from multiple viewpoints, making comparisons, pondering ideas and following leads. She has discussed that one develops theoretical sensitivity through theorizing. She defines theorizing as "stopping, pondering and thinking anew" (p. 135).

Charmaz's ideas coupled with Schwandt's (1999) presented some difficult challenges for me. During initial phases of the study I thought I was quite open to new ideas and new ways of thinking, but as the study progressed I continually had to face that I was very locked into a special education mindset that I didn't even know existed before I began writing this dissertation. Skrtic (1995) has observed that the process of socialization into the profession of special education is an essential part of professional training. He explains:

When students can demonstrate that they have internalized the profession's knowledge, skills, norms and values-how to think and act as professionals-they are duly certified by the professional school, admitted to the professional community by the relevant professional association, and licensed by the state to practice the profession (p. 11).

However, the beliefs that underlie policy and practice are often unacknowledged and unrecognized, even by those who teach them (Kalyanpur & Harry, 1999). Bowers (1984; 1995) has commented that this leads to knowledge that is "taken for granted" and assumed to be "the natural order of things" (1984, p. 36). According to Kalyanpur and Harry (1999) special education is full of these entrenched beliefs.

Skrtic (1991) further posits that because special educators are often positioned within the paradigm of objectivist thought, they often view their professional world in a particular way, and teacher preparation programs typically do not ask nor require students to acknowledge other theories of knowledge. In fact, both professionals and in turn students are often unaware that discussion exists pertaining to other theories of knowledge. Indeed, according to Skrtic (1991) criticisms of special education have rarely centered on "assumptions, theories and metatheories, but instead on the efficacy of models, practices and tools" (pp. 55-56). In retrospect, I can now see that my decision to choose grounded theory as my research method was influenced by my taken-for-granted assumption that I needed a "model" to follow.

Grounded theory appealed to me as a research method because it seemed to offer a set of “rules” which I felt provided me with something to hang onto during the nebulous research process. In retrospect, I did not choose the method because it was best suited to my question; that is not to say that grounded theory was not a suitable method for my study. The problem for me was that at the beginning stages of research, when I needed to choose a method and design a study, I did not fully comprehend the implications of saying I wanted to do a qualitative study from an interpretive rather than post-positivist stance. This in part I feel was due to my successful indoctrination into the profession of special educator. While this lack of understanding had implications for the interview process itself, its most profound impact came when it was time for me to interpret the interview texts.

I was drawn to using grounded theory method as it would give me the opportunity to interview parents which I was very interested in using as a procedure of my study. Having worked for almost two decades with families and their children, it was very appealing to me to be able to take the time to talk to families about issues that I felt were important to them and interesting to me. Furthermore, grounded theory builds on a strong practitioner as researcher framework and I felt at the time, and still do, that my practitioner skills are one of my strengths. However, those same skills that I saw as one of my strengths also seemed at times to conspire against me as a novice interpretative researcher.

In retrospect, it seems to me to be an interesting paradox, that in order to be considered a quality special educator one must be at times inordinately concerned with goals, objectives, assessments and measurements of efficacy. On the other hand, in order to work effectively with young children with disabilities and their families, one must be compassionate, willing to listen, flexible and empathetic. During my special education training and certification process much of

my Masters degree work focused on strategies to use in the classroom with course titles such as: the education of the severely and profoundly handicapped, assessment of the exceptional preschool child, instruction of the mildly handicapped, and research methods for handicapped groups. These courses taught me how to write excellent IEP's and measurable behavioral objectives, they also taught me what effective teaching strategies to use in a classroom setting, and how to use current assessment measures. At the completion of my Master's degree I felt armed with much of the professional knowledge I would need to be an effective teacher.

To be fair, working compassionately with families was also discussed during graduate school in the form of a field placement where I worked and observed one family of a child with a disability. In addition to meeting with the family each week, I also met with other students and faculty every other week to discuss our families and other issues. This experience was invaluable and the discussions that took place were always interesting and provided me with many learning experiences. I often told people who asked about my graduate work that meeting and working with a family was one of the high points of my program that provided me with a wonderful experience and much knowledge. However, this placement was worth one credit out of a forty plus credit graduate degree program.

This is not meant in any way to be an indictment of special education programs. I feel I learned an immense amount in both my Master's and doctoral graduate programs; and because of my education I have been able to consistently work in the special education for almost twenty years. I also think programming has changed since I was a full-time Master's degree student, and the family piece is addressed in a deeper and more systematic way.

However, it has been my experience that learning strategies and "best practices" continue to take precedence over learning how to be a compassionate and flexible listener. Therefore, as a

practitioner, particularly when I was new to the field, I would often find myself shifting between the two parts of my professional life: goal oriented special educator or compassionate, listening special educator. Depending on the task at hand I chose which part of my professional personality would show up to do the work. On many occasions I would shift my mindset midstream during a session if that is what the situation seemed to warrant.

In my day to day practice, this left me feeling uneasy on many occasions. I would leave homes wondering if I gave the family enough of my time, my knowledge, my patience? Was it okay that I only provided a shoulder to cry on instead of providing concrete information and links to other support systems? Was it okay that I gave them lots of information-maybe too much information? Although I would sometimes feel personally uncomfortable this issue did not seem to hamper my professional life. The problems began to surface when both of these worlds began to collide in the form of dissertation research.

Confronting many of these questions made me feel at times so unintelligent and dim that I would regularly question myself and my intuition, and bursting into tears was not an uncommon occurrence. How could I not understand so many things about the nature of the human experience? How could I even call myself a good teacher? What had I been doing for the past fifteen years in early intervention? These are not good questions for a doctoral student to be asking herself. To say I was wracked with doubt would be an understatement. However, near the end of my doctoral program I stumbled upon the work of Thomas M. Skrtic (1991; 2004).

Much of what he wrote helped me to understand where I had been and where I was attempting to go. He wrote that as a new professional in special education he began to read more broadly in a variety of social disciplines in an attempt to understand the field in a broader way.

During this time of personal discovery, he commented, “I began to question, my own doctoral training in special education and that of others who, like me (I had to assume) had not been exposed to the ideas, authors, disciplines, or frames of reference that I encountered in my reading. What did this mean socially, politically, morally?” (2004; p. 269). He has written in depth about the underlying assumptions of special education including the idea that special education was created in order to remove and contain difficult students so that the order of public schooling could remain in the general education setting.

Skrtic (1991; 2004) has discussed four assumptions of special education: disabilities are pathological conditions that students have; diagnosis is objective and useful; the purpose of special education is a coordinated system of services that benefits diagnosed students; and progress results from rational technological improvements in diagnostic and instructional practices. He posits that the practice of special education is a quest for “rationality, order and certainty in the field of education” (2004, p. 97). His ideas helped me to examine my discomfort and my questions under a new light.

These unexamined assumptions about special education led me down a narrow path when I began to contemplate my dissertation research. Initially I had some general knowledge and ideas regarding how I would “do grounded theory.” I assumed I would interview families to find out how they viewed and approached supporting the social relationships of their children with disabilities. I imagined I would discover, through the interview process, a set of “strategies” that either worked or didn’t work for families. I would in turn translate those parental accounts into a document that illustrated practical relationship building strategies that parents used. Early intervention practitioners could then implement these strategies and suggestions. My thinking about the topic and the research process was quite linear, and dovetails with Skrtic’s (1991)

discussion of special education as a technical-rational field. A simplistic chart depicting my imagining of the process and subsequent results, moving from bottom to top, is provided in Figure 1.

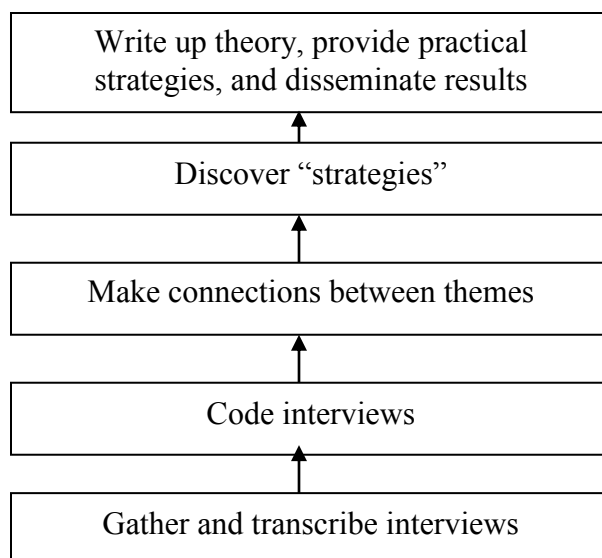


Figure 1: Technical View of Theorizing

My thinking in part was based on my experience in the field of early intervention where focus is often on the delayed development, including social development, of children. As a practitioner, I have often felt that part of my job was to help families “fix” these social development issues in order to deem my involvement with them as successful. However, I began to see that my idea of fixing things was often different from what families wanted to “fix,” and I left many interviews thinking about ideas and perceptions that I had not anticipated.

According to Skrtic (1991) my original implicit understandings and assumptions can be traced back to epistemological and organizational underpinnings of the special education system. Kalyanpur and Harry (1999) have referred to these underpinnings as the “culture of special education” (p. 3). Skrtic (1991) has argued that because the field of education has valued positivist conventions of understanding, services tend to be of a mechanistic nature. Both Skrtic

(1991) and Schon (1983) have discussed how the view of teacher is often based on a model of technical rationality. Skrtic (1991) has stated that special education is a “more extreme version” (p. 105) of this view than regular education, with the special education teacher “conceptualized as a technician” (p. 106). Furthermore, in evaluating where a variety of social sciences fall in regard to research beliefs, Skrtic has stated that the field of special education is located “in the most extreme objectivist region of the functionalist paradigm” (p. 106).

Moreover, Kalyanpur and Harry (1999) point out “because most professionals who come into the field have demonstrated through their success in the education system mastery of the belief system...most new members” generally do not examine the cultural underpinnings of the field. In fact, Kalyanpur and Harry go on to say, “the rules of the cultural institution may never be taught explicitly to new inductees because the insiders themselves may not be aware of the rules” (p. 9). In other words, professionals in the field of special education rarely address cultural and epistemological beliefs; they are typically not part of the pedagogical process in part because teachers may not even be aware of their own beliefs and assumptions.

I began to understand why Kalyanpur and Harry (1999) referred to special education as a low context culture. They base their assumptions on the work of Hall (1981) and discuss that when actions and situations are “decontextualized” (p. 7) it is assumed that the intervention can be conducted by “anyone anywhere and still have the same meaning in all contexts” (p. 7). I understood that social relationships were exceedingly complex, but I was also discovering that complex contextual issues also surrounded each practitioner, each family and each social relationship. In fact, social relationships seemed to be so wrought with issues that I had never considered as a practitioner that some families were reluctant or unwilling to discuss them.

Consequently, finding a set of strategies that would work in a variety of contexts and improve the social relationships of young children with disabilities began to seem unfeasible to me.

During the collection of interview text and the coding and analyzing of the text a shift began to take place moving me from the original intent of my study of understandings of parental views of social relationships to broader understandings of parental views of parenting a child with a disability. I did realize at some point that my understandings were moving away from social relationships; in fact this idea sent me into a panic on more than one occasion. Perhaps the realization that discovering a set of strategies that could be generalized from one family to another no longer seemed possible made me more susceptible to drifting from the original intent of my study. I don't know. I do know, however, that I pushed those fears aside instead of using them to prompt meaningful discussion. Even when parents specifically said they did not want to talk about social relationships in any depth, and I realized that pushing the conversation down this path made me uncomfortable and seemed to be unethical, I still did not allow myself enough flexibility to pause, reflect, and go where the text was taking me.

In some ways this demonstrated a great lack of theoretical sensitivity. However, although I had great difficulty articulating and understanding these issues and concerns in any depth, I did in the end follow my instincts as a practitioner, and my instincts told me that although parents were not discussing social relationships in depth at each interview, what parents were sharing with me was valuable. And so I continued down my path of understanding which was now littered with technical terms and viewpoints that I was attempting to simultaneously discard and cling to with all my might.

Unexpected Ethical Considerations

Although one of my original intents had been to talk about present social relationships and what parents expected for the future, I found myself unwilling to direct parents toward a discussion of the possibility of a friendless future for their child. My technical self knew what the literature said about the friendships of children with disabilities, and how children with disabilities typically have great difficulty in this area. However, I found myself unwilling to push the issue. The brief descriptions and interview excerpts below may help to illustrate my reluctance to push parents to think past the present.

Dawn is a married mother of two boys who works part-time as a family advocate for children with disabilities. Her older son, Bradley, aged 6, has been diagnosed with Asperger's syndrome, and her younger son, Ben, aged 3, has been diagnosed with developmental delay. Bradley had recently finished his Kindergarten year in an inclusive setting in the public schools. By her account the school year went exceptionally well. She said, "Kindergarten has been so fabulous so I am hoping we don't have a big letdown for first grade." We talked about the friends he had made and how she would be happy if he ends up with a couple of good friends. I then asked her what would be her worst-case scenario for friendships for her son? She replied:

I don't think about it, because I could go to some very dark places and I have a feeling if I verbalize it I will be up at three o'clock this morning thinking, 'Oh my God...' I can't go there.

All of the families echoed these same sentiments in some way. Bonnie is also a married mother of two, who works part-time. Her daughter Eva was five years old at the time of the interview, and will be starting Kindergarten in the fall of 2006 at a Catholic school. Her son, Caden was three years old and attended a private specialized preschool with other children with special needs and a few typical classmates. He was diagnosed with PDD-NOS at around

eighteen months of age. Bonnie had been talking about how well the school year had been going, and how a few days earlier she received a note from the school saying that Caden had started showing an interest and a desire to play with some of the older kids in his classroom.

Bonnie had this to say:

Next year his preschool might not even be there because right now they have only five kids signed up. I don't even want to think about that. He's done so well there and I would have to figure something out obviously. We'll cross that bridge when we come to it. It's a lot of uncertainty with a child who has a lot of uncertainty.

These examples are just a few of many where parents openly stated that they could not or would not spend too much time thinking about what may lie ahead for them or their children because it was both stressful and non-productive. I did not feel it was my place to take away anyone's hope for what the future may hold. Initially, I felt that it might be due to my prior relationships with families, which led to a personal discomfort of wanting to avoid discussion of difficult issues. I was also averse to broaching a sensitive subject and then leaving parents alone to deal with the after-math of the discussion.

I was unsure how to deal with this unexpected issue. I turned to the existing literature and I found that the parental comments I had heard seemed to mirror the thoughts of others when faced with chronic conditions. S. Kay Toombs (1995), Ph.D., a university professor who was diagnosed with Multiple Sclerosis twenty years ago says:

There are thoughts that come unbidden in the night to reawaken my deepest anxieties. There is no way for me to look them in the face and remain intact. I must push them back. Back into the recesses of my consciousness. It is an act of will. I must think only of now. Of this day. Of this moment. Of what I have. Of what I can do. Of what gives me joy. Please, let me think only of this. Sufficient unto the day is the evil thereof. (p. 22).

This passage led me to contemplate the importance to families of living one day at a time.

Immersing myself in a variety of discursive texts (Garman, 2006), such as the example above, helped me to begin to challenge tacit assumptions that were embedded in my personal experience. I looked not only to special education literature, but also to select pieces from other bodies of literature including, but not limited to, nursing, medical ethics, theology, and biology. This exploration of the literature helped me to answer questions and also heightened my awareness of issues that have been explored by other researchers. However, this initial opening myself up to uncertainty and new and unfamiliar discourses was very disconcerting and I began to move farther away from the original intent of my study.

Therefore, if parents did not begin to discuss the possibility of a friendless future for their child on their own or after a few subtle attempts by me to move the conversation in that direction, I often dropped the subject. Due to my lack of a counseling background and lack of basic counseling knowledge, I found that parental comments regarding a desire to not think about the social future of their children often left me feeling ill-equipped to deal with the discussion. Additionally I was quite reluctant to leave parents upset if I broached this possibility in a more pointed manner.

Reflecting on the parents' comments about the future, and the comments by S. Kay Toombs made me cognizant that topics I had not initially anticipated as being difficult to discuss were indeed quite difficult for some families. Furthermore, when I came up against raw emotion I backed away. This influenced some of the questions I was willing to ask and some I intentionally avoided, and had a definite impact on my ability to attend to the concept of theoretical sensitivity in the manner that an interpretive grounded theory study requires. I think it also influenced how I analyzed and coded the text.

Theoretical Sampling

As one collects interview texts, the emerging ideas and theory should have directed me to sources and ideas I had not originally considered (Brantlinger et al., 2005; Charmez, 2000; Charmaz, 2006; Grubs, 2002). This is known as theoretical sampling (Glaser & Strauss, 1967). To a degree, theoretical sampling helped to direct me where to go with each new interview (Charmaz, 2006).

According to Charmaz, theoretical sampling is a strategy that helps to define and develop hunches and categories. As various concepts and ideas became compelling to me, I did direct my questions to sometimes new and different areas to help push my understanding forward of this complex topic and to elucidate emerging ideas. Additionally, if a concept was interesting to me, but seemed thin or underdeveloped I would ask questions specific to that category in subsequent interviews in an attempt to strengthen the category and flush out more full-bodied meanings (Charmaz, 2006).

During this process I looked for particular information that illuminated and defined the emerging categories and theory (Charmez, 2000). Theoretical sampling sometimes entailed returning to previously interviewed individuals, or interviewing new individuals to fill any conceptual gaps (Charmez, 2000). The purpose of theoretical sampling is not to provide a larger sample size per se, but to elucidate points or clarify images (Charmaz, 2000). On several occasions I called mothers on the telephone after the formal interviews were completed in order to clarify points. Sometimes this process took the form of a simple follow-up question, and once or twice after I had done some thinking and writing about an interview a different question arose that I felt the need to ask.

However, as with theoretical sensitivity, I learned much about theoretical sampling in retrospect. Because I was so entrenched in my special educator professional mode, the mode that focuses on goals and objectives and finding strategies that would work, I often did not ask questions that in hindsight would have been illuminating. As with my levels of theoretical sensitivity, I feel that at times I did an excellent job with sampling and at other times I had difficulty shifting from attempting to find an answer to simply listening and absorbing the stories parents were sharing with me.

Furthermore, my lack of experience with interviewing family members also proved to be problematic at times. Through my practice I had often sat with parents and listened while they talked to me about issues or concerns. However, those conversations were almost always directed by the parent's needs. During the interviews for my dissertation I was much more tuned into getting the information "I needed" in order to complete my study. Sometimes this single-mindedness had a negative impact on my listening skills. Furthermore, I was often concerned very basic worries such as my tape recorder not working, or making sure I was taking detailed notes in case my tape recorder did not work. I feel that the combination of these issues and concerns impeded my ability to effectively direct my questioning in a more focused and thoughtful and manner. I now turn to specific procedures I utilized to complete the study.

Coding, Memoing, and Constant Comparative Analysis

Coding is the first step in theory development (Charmaz, 2000). At the conclusion of the first interview, I began the coding process. I initially looked for words, phrases or passages that were related to social relationships, friendships, and acceptance. I also examined text that included comments about what or whom parents viewed as providing support *for* or a barrier *to*

their children's social relationships. Additionally, any concepts that seemed particularly insightful were flagged with a code.

Instead of using line-by-line analysis, which according to Rennie (2006) can become cumbersome and may lead to the microanalysis of main concepts, I examined the main points or themes of any given passage. Rennie (2006) has coded in a similar fashion; the researcher determines what constitutes a passage, and codes the concepts that are implicitly important to him or herself depending on what is under study. Rennie has named these passages meaning units or MUs and has stated, "In deciding what constitutes an MU, the analyst is alert to the main point or them of any given passage" (p. 67). Therefore, sometimes passages are coded line by line whereas others would be coded in larger thematic chunks, depending on what the researcher sees as the important point or points in any given passage (Rennie, 2006).

My initial codes drew on the precise language found in the text that I as the researcher "explicitly or instinctively sense are important" (Piantanida et al., 2004, p. 339). When possible I used the respondent's language to code described by Glaser and Strauss (1967) as an *in vivo code*. This coding process helped me to gain a perspective on the interview text, to focus my data collection, and to facilitate making comparisons (Charmaz, 2000). An example of some of my first codes from my first interview is provided in Figure 2.

| <i>Interview Text</i> | <i>Initial Codes</i> |
|---|--|
| Some of the forms were really invasive about your marriage and other stuff. So I didn't want to rock the boat so I did it. I did it a few times and then thought this is none of their freaking business. I finally asked if this was required and they said, "No." I should've asked. I'm smart enough to know better. | Invasive, personal info. Didn't want to rock the boat Finally asked if was required; not required Smart enough to know better |

Figure 2. First Codes from First Interview.

However, after coding the interviews, meeting with colleagues and continuing to read Charmaz, I felt that I was not grasping the richness and depth of the interviews. I began to feel that I was coding for “themes” as Charmaz (2006) says, which leads researchers toward a descriptive theory instead of a more complex understanding of theoretical connections between codes. Therefore, in keeping with both Glaser (1978) and Charmaz’s (2006) suggestion, I recoded each interview using gerunds. This method “fosters theoretical sensitivity” (p. 136) by moving the researcher out of static descriptions and categories and into a more process oriented way of thinking. By coding with gerunds, I was forced to focus on actions, which set the stage for seeing sequences and connections among the codes. The same interview excerpt is shown in Figure 3 with my second set of gerund codes.

| <i>Interview Text</i> | <i>Gerund Coding</i> |
|---|---|
| Some of the forms were really invasive about your marriage and other stuff. So I didn’t want to rock the boat so I did it. I did it a few times and then thought this is none of their freaking business. I finally asked if this was required and they said, “No.” I should’ve asked. I’m smart enough to know better. | Feeling invaded by system & paperwork Feeling questions were too personal Avoiding “rocking the boat” Complying; doesn’t want to “rock boat” Getting angry Asking questions finally Getting braver Blaming self for not asking & for not trusting self |

Figure 3. Second Codes from First Interview: Coding with Gerunds.

Utilizing the gerunds to code helped to push me toward a deeper way of thinking, but did not entirely solve the problem. I attempted to move away from themes and in some regard I was successful. However, because I continued to look for precision well into the research process I did not mine the full power of the text.

During the coding of the interviews I also began memoing. The memoing process began with the conclusion of the first interview. Memoing involves capturing ideas through the

interplay of the texts and is one of the cornerstones of grounded theory (Glaser & Strauss, 1967; Glaser, 1978). Notes were written, inferences made and changed, and links were examined. Writing memos helped me to incorporate my ideas about the interview text, and provided a bridge between my codes and the first written draft of a theory (Charmaz, 2000).

I wrote memos on copies of the stable interview texts. Additionally, I kept a journal throughout the dissertation process where I jotted down ideas or conversations that occurred outside of the interview process that helped to inform my thinking. The memos and journal entries included my thoughts on the interview text, preconceptions or hunches that I had, any sense of relationship I felt among the codes, and ideas on what the core category may be (Rennie, 2006). In Figure 4 the same interview text is provided once again with the memo column added.

| <i>Interview Text</i> | <i>Gerund Coding</i> | <i>Initial Memos</i> |
|---|---|---|
| Some of the forms were really invasive about your marriage and other stuff. So I didn't want to rock the boat so I did it. I did it a few times and then thought this is none of their freaking business. I finally asked if this was required and they said, "No." I should've asked. I'm smart enough to know better. | Feeling invaded by system & paperwork Feeling questions were too personal Avoiding "rocking the boat" Complying; doesn't want to "rock boat" Getting angry Asking questions finally Getting braver Blaming self for not asking & for not trusting self | This mom has talked more than once of the invasiveness of the system. Are we as family-centered as we think? Advocacy of some sort also seems to be a recurring theme for her. I find it interesting that she was unwilling at first to rock the boat, especially since she is a lawyer. I wonder why she was/is hesitant? |

Figure 4. Codes and Memos.

These initial memos were expanded in journal entries sometimes minutes, hours or days after the completion of the interview. Additionally, if I read an article, or had a conversation that

caused me to reflect on something I had heard in an interview I wrote it down in my journal. As Glaser (2001) said “all is data.” An example of a journal entry is provided in Figure 5. This particular entry was written after I had completed my third interview.

I feel like each interview thus far sheds light on both the beauty and cruelty of humanity. I often leave feeling more inadequate than I anticipated as an EI teacher and interviewer. Transcribing helps me to better see the richness of the exchange. All three moms so far are not afraid to advocate and speak up. All three also said that friendships are not especially important at this point in time-no matter how I worded the question. Yet, all three went on at length regarding choices they had made regarding school placements, (reminds of Guralnick article), education others, involving child in community activities in order to help child with self esteem, social skills, relationships, acceptance, etc. Do parents see the connection? Is there a connection? I think so.

Figure 5. Journal Entry.

As the number of interview texts grew, I continued to code and memo. I coded each interview on a hard copy of the interview transcript. I then transferred each code to an index card that was referenced on the back with the initials of the interviewee and the page number from which the code was pulled. These cards were all laid out on a table so that I could move and shift cards and ideas in order to begin to make comparisons and inferences. Comparing the codes began the process of conceptualization that allowed me to put the information parents have shared into some perspective, and to begin to understand their importance. As more codes emerged, they were grouped together and connections were made. This gathering and analysis of text happened concurrently and was interactive (Rennie, 2006). The aim of this process was to move from iterative to conceptual interpretation (Piantanida & Garman, 1999; Piantanida et al., 2004).

Constructing the Ground –Attempting to Move Toward the Portrayal of the Experiential and Theoretic Text

To warrant the theory I was striving to construct, it was necessary to portray the ground about which I was theorizing. When the ground is portrayed with sufficient verisimilitude, it “allows others to vicariously experience the phenomenon and the context under study, and thereby come to understand the complexity of both” (Piantanida & Garman, 1999, p. 133). In order to portray the ground I had to move from the interview text to the experiential text (Garman, 2006). According to Garman (2006) the experiential text is a description of not only “what happens when” but also the author’s interpretation of why and how (p. 6).

I had coded each of the interviews and had delineated concepts that were thought provoking to me and to my practice. However, by focusing on the concepts, supported with excerpts from the interviews, I did not seem to be portraying the richness of the conversations that I had participated in with families. Therefore I began to write narrative vignettes to help to capture the depth of emotions and experiences that families had shared with me. Utilizing the vignettes provided a way to present readers with a sense of the ground, while allowing me to continue to examine personally compelling theoretical concepts that came out of the parental interviews. Additionally, by using these vignettes to portray the ground I hope to demonstrate how Charmaz’s (2006) idea that “ordinary experiences shine with bright meanings” (p. 151) may relate to the practice of early intervention.

Throughout the dissertation I struggled with my concept of the ground and how it would best be portrayed. In early drafts I placed sections of my theory in the foreground and the narrative vignettes in the background. I did this because at the time it made sense to me to place my “answers” in the form of theoretical concepts first and then give the reader the family stories that led me to those conclusions. In retrospect I think this relates back to Kalyanpur and Harry’s

(1999) idea of special education as a low context culture and the common assumption that it is necessary to decontextualize ideas and concepts. By decontextualizing concepts it is assumed that interventions can then be conducted by “anyone anywhere and still have the same meaning in all contexts” (p. 7). I felt that by placing the concepts up front and separate from the stories and therefore would be more accessible to other early intervention practitioners who may read the document.

During the writing of my dissertation I met every three weeks with a study group that consisted of faculty members, teachers who had already received their degrees, and other doctoral students. After several discussions with study group members, many of whom were trying to help me to understand that with interpretive modes of inquiry the portrayal of the ground is more often than not best served at the forefront in order for the concepts to emerge from the ground, I acquiesced and placed the ground first, followed by sections of more theoretical thought.

After this change was made I gave the draft to two doctoral colleagues, both of whom are also practitioners in the field of early intervention. Upon completion of reading the draft, they both commented that they didn’t really understand the narrative pieces. They struggled in the same places that I did. Therefore, I once again rearranged sections, placing theoretical ideas before the ground, and gave the paper to both colleagues to read once again. A few days later, one colleague contacted me and said, and I paraphrase, “Oh I get it now, you are showing the reader the ground with those stories, as in ‘grounded theory.’ ” I once again veered away from the most challenging aspect of portraying an inductive qualitative study without really understanding why I was having such difficulty working within the flexible conventions of constructivist grounded theory.

However, I turn to Charmaz as she states “whether the theory remains embedded in narrative or stands out in bold relief depends on your task and your rendering of it” (p. 173). I saw my task as twofold. One, right or wrong, as trying to build a bridge between the two factions of my committee; and two, as more importantly trying to build a bridge between the two parts of myself, the known “technical, special educator self” and the new “deliberative special educator self.” This departure from constructivist grounded theory of initially placing the decontextualized concepts before the families’ stories provided for me a means to begin building the bridge. For my final draft I did move the family stories to the forefront, and began to finally understand why they should be there, and how more depth would be helpful with particular concepts. However, I did not have the courage and often times understanding of method and language to move my ideas from a more rational-technical framework to a more deliberative one.

Furthermore, I contemplated in vain for many months to construe a core category that would hold my conceptual concepts together as described by Glaser and Strauss (1967). However, then I read Charmaz’s (2006) account of attempting to construe a core category for a period of years. She discussed how she eventually did settle on “experiencing illness” and that as a core category this idea did hold her other concepts together, but in retrospect she felt her core category was so broad that any number of constructs could have been related to it, and in the end it did not add much to her theoretical portrayal. She discussed that at times a core category makes sense, but not always.

All of these ideas began to free me to a degree from rigidly thinking how I should construe my theoretical concepts and categories and in the end my portrayal of the theoretic text. The theoretic text “represents the author’s personal theories” (Garman, 2006, p. 6). My new

understandings of special education began to lead me to a different visual interpretation of theory, as shown in Figure 6 that was quite different from my initial linear model.

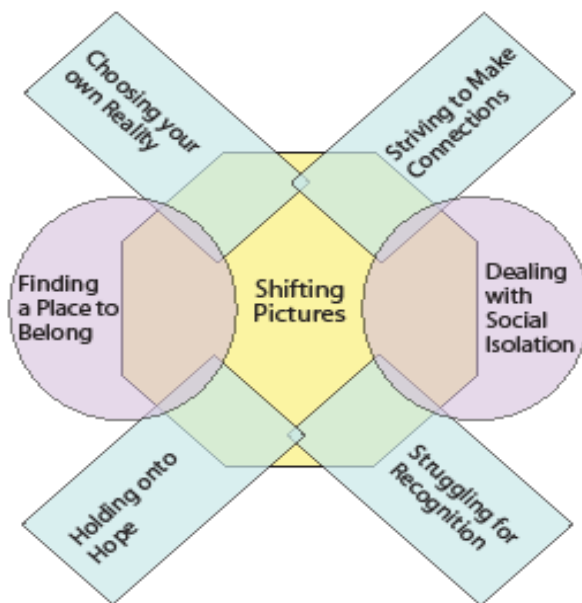


Figure 6. Toward a Substantive Grounded Theory – Living with Shifting Pictures

The theoretical portrayal I have created, based on the interviews I completed, draws on a metaphoric representation of a kaleidoscope. Using metaphors to present unfamiliar information has been recognized as a means to elicit growth and understanding by allowing new knowledge to be conveyed using familiar frames of reference (Campbell, 1988; Guiffrida, Jordan, Saiz & Barnes, 2007; Langer, 1948). The kaleidoscope metaphor is used throughout the remainder of the dissertation, and represents a move from a more strategy-oriented vision to a more meaning-oriented one.

As Charmaz (2006) has pointed out, it can be difficult “to recapture the fullness of events through our analytic renderings” (p. 151)? She acknowledged that “the emergent character of grounded theory writing may conflict with report or dissertation writing,” and that “required

formats often presuppose a traditional logico-deductive organization. Thus we need to adapt the format rather than pour out our work into standard categories” (p. 154). In keeping with Charmaz’s words of wisdom, I attempted to adapt, and did indeed achieve a move that was fairly distant from where I began. However, the ground and theoretical portrayal I ultimately crafted should be viewed as the beginning of my journey and not the final destination for I have learned that there is still much learning to be done.

Chapter 4: Dichroic Glass Portrayal of the Ground-Living with Shifting Pictures in a Kaleidic World

Chapter Purpose and Organization

Charmaz has discussed how it is important to take the reader into a story by moving “beyond an analysis of acts and facts” (p. 172) by attempting to impart mood, context and emotion. Therefore, chapter four is offered as the weaving of the acts, the facts, the moods, the contexts and the emotions into a portrayal that will answer guiding question number three: What is the ground of parental meanings from which I am theorizing? Chapter four begins to highlight my core concept of living with shifting pictures, also referred to in the paper as living in a kaleidoscopic world. This core concept reflects how the parents I interviewed seemed to live with constantly shifting mental pictures of their children’s past, present and future. It appears that parents sometimes shift their own pictures, much as one would turn the wheel on a kaleidoscope to change the view. However, sometimes others, family, friends, professionals or even strangers, shift the pictures by purposefully or inadvertently touching the carefully balanced kaleidoscope to shift the view into something else. Parents seem to shift their pictures for a variety of reasons; the reasons I found most interesting were their attempts to shift toward the idea of belonging and away from social isolation.

This chapter provides narrative vignettes that I created in order to explicate the concepts of my theoretical portrayal. A section entitled *Professional Reflections* follows each vignette. Much has been written about using professional reflection as a means to sharpen perceptions of common methods and approaches to challenging situations (Wesley & Buysee, 2001). For these reasons, I utilized the *reflections* format as a means to deepen my understandings of the complex situations with which I was confronted.

It is important to note that this portrayal is my interpretation of the experiences parents shared with me, and the parents I interviewed may or may not agree with my interpretation. I begin with the vignettes related to choosing a perspective. By utilizing the vignettes I hope to elucidate some of the complexity of each family, and some of the unique strengths and challenges each family brings to early intervention professionals. This complexity adds to the already multifaceted job of early intervention practitioners. For some of the concepts with multiple vignettes relationships among ideas are presented within the practitioner reflection section of the last vignette.

Bianca's Story

I had never met Bianca before our interview. She was very welcoming and told me that she agreed to be interviewed as she has a sister who recently completed her Ph.D. As we walked back to her kitchen Bianca said to me as she laughed, "My sister would never forgive me if I didn't agree to help you out!" She shared that her son was upstairs sleeping so we had a small window of opportunity to talk. His name was Matt, and he was three and a half years old. He had been diagnosed with PDD-NOS, a form of autism. He attends an early intervention classroom two mornings a week, and receives speech and language services.

As we got settled at her kitchen table Bianca said, "He has a very high activity level and has therapeutic support staff (a TSS) that goes to school with him. Safety is a pretty big concern for us." Bianca talked about her husband, who works as a truck driver, and she told me that she works as a musician and voice teacher. "I am lucky that I can arrange my work schedule around my kids. Matt has an older sister who is in first grade. Having flexibility is key for me because we don't have any family in the immediate area. I mostly rely on friends from church if I need someone. That is mostly who we socialize with also."

Initially Bianca suspected that Matt had ADHD because he was so active. His high activity level poses an ongoing concern for her, as he has escaped from a number of events and activities resulting in dangerous situations. Her husband has moved switches in their home and has replaced locks in order to help keep Matt safe. Bianca shared one incident that was particularly dangerous.

“Well, after he was diagnosed we didn’t tell everyone. And right around that time we went to watch my daughter’s dance recital and they had a babysitting center set up in another room for the performer’s siblings. I was so excited when I found that out because then I knew I could relax and watch the show. About halfway through the show I went to check on Matt and I overheard one of the mothers talking to another mother about how she had just found a young boy wandering out in the parking lot. I knew, I just knew. My heart stopped. I said, ‘Did he have on a yellow t-shirt?’ And she said, ‘Yes, he was outside by the street in the parking lot so I brought him back in.’ I went back into the daycare and I didn’t freak out but I did tell them they could’ve had a tragedy on their hands. They were very apologetic, but it was my fault too, because if I am not up front with people about what they are dealing with... Well, the next day, I figured I better get everyone on board so I sat each of my friends down and our regular babysitter and I filled them in.”

Bianca later shared that although all of her friends knew about Matt’s diagnosis many members of her family did not, including two of her three sisters. “You know sometimes family is just too close. Friends are like my reality checks, and they will tell me the truth. Two of my sisters don’t know about Matt’s diagnosis, but the shit will hit the fan this summer because we are all going on vacation together. It will be hell for me. I just don’t want him destroying the house and running into the ocean. My one sister will tell me I have to discipline him, and the

other will try to convince me nothing is wrong, and I don't want that dynamic. We don't live near them so maybe they don't even have to know. We'll see."

She talked about how a friend had initially suggested that Matt might have Asperger's Syndrome (AS), but she dismissed the idea. At that point in time she said, "I knew that AS was on the autism spectrum, because I knew a child who had been diagnosed, but Matt made good eye contact and so I totally didn't agree with my friend's concerns." However, as time went on she became worried about Matt's behavior and when he was diagnosed with a speech delay the speech therapist also raised some concerns about Matt's development.

When Bianca decided to pursue an appointment with a developmental pediatrician she said she didn't feel especially prepared for the diagnosis, but she also wasn't surprised. When I asked her how she learned that Matt had a disability, and how she remembered the process she said, "Well, I was a little bit prepared and I am weird. A few months ago I saw a show on TV about a little girl who didn't have a face. When she was born they basically sent her home to die, but she didn't die. She will need something like 200 surgeries...So anyway, I was flicking around and I saw this and I almost threw up, but then I said to myself, 'Bianca, you are a staunch pro-lifer you go back and watch that.' And so I did and I decided, 'My kids don't have any problems.' That doesn't mean I am going to deny it and sweep it under the rug, but at the same time, they can walk, they can talk. I mean it is perspective. Things can also be a zillion, billion, unimaginable times worse. So every day that I keep him safe and alive is a miracle. I was not going to get upset about it, no way, it's silly."

Professional Reflections

Bianca seemed to be making a conscious decision as to what her version of reality would be on her life and her son's disability. As I read other interviews it seemed that parents

were quite intentionally making meaning by choosing a particular perspective and a particular lens through which to view their children's lives and by extension their own. Parents seemed to reach this point through different understandings. Some, like Bianca, compared their life to the life of another child or family who seemed less fortunate. The general thought process seemed to move parents toward a point where they said to themselves, "We could be in that situation, but we're not. Our situation is much better and more manageable. I'll take my situation any day over the situation of others. I can consider myself lucky. Things will be OK."

However, other parents didn't seem to compare their situation solely to that of others. Instead, these parents seemed to feel that whatever disability their child had was manageable in the sense that through understanding themselves, they felt they could deal with a particular disability. For example, "I can deal with a physical disability, but if my child had mental retardation I could never do it." Or, "I feel I can handle Down syndrome. I know what to expect and there are a lot of support groups and information about it. Plus, other people recognize it and know immediately what my child has." Parents that made meaning in this manner, I entitled "understanding self." Dawn provides an example.

Dawn's Story

Dawn is married and works as a special education family advocate. She has two young sons with diagnosed delays. Bradley, her older son, has been diagnosed with Asperger's Syndrome (AS), and her younger son has been diagnosed with both developmental and speech delays. Bradley attends his neighborhood school and had just completed his Kindergarten year. Ben attends an early intervention preschool program two days a week and also receives speech and language services and physical therapy.

I had also never met Dawn before the interview and I was surprised at how open and candid she was. I went to her house and we sat on her back deck so she could keep her eyes on her two young sons splashing in a kiddie pool that was set up in her yard. She used humor through out the interview, making jokes about her life, her children's delays, and a variety of other things. She talked about how she made jokes to help her cope, and to help her see the humor in every situation. Some days she said were certainly more difficult than others, but she felt that keeping a good sense of humor about things helped her to stay positive.

She shared, "Well, when you have a kid with autism...I was like that before, making jokes all the time, and it is a great coping strategy. I mean there are days when autism rears its ugly head, like yesterday I was talking to a girlfriend about it and I told her that Bradley doesn't get sarcasm. And she said, 'That must be killing you.' I told her she has no idea [laughing]. There are times when you can't find the humor, but if you step back and realize, OK. There was a point yesterday when all I wanted was a glass of water. It was poured and sitting on the counter and for an hour and a half between kids, and the dog, I couldn't get a drink. And finally, I was like, I don't even want the water anymore where's the beer?" [Laughing].

Dawn remembered back to when her older son was diagnosed with Asperger's Syndrome. "When he was around four and he was in preschool the teacher raised some concerns. I always used to joke about it so I think I always knew in the back of my mind. I used to call him 'Rain Man' and stuff. But the day the teacher told me surprisingly enough I was taken by surprise. She was like, 'You need to call to get him evaluated,' and I remember the date, it was December 3rd."

"I started calling everyone I knew in special ed., my friend who is a speech pathologist, and one is a teacher and I was getting him out of class. I was like, 'Oh my God, oh my God.' I

got him appointment after appointment, and I then I just had to sit back and wait. And after all that when they came back and initially gave us a diagnosis of PDD I thought, Really? I thought you might say he was normal.” She continued, “I am an educational advocate who works with so many families and I am still not prepared. Sometimes you are just not prepared for the difficulties that arise.”

I asked her what the parenting experience had been like for her and she responded, “All in all I think it’s been a good experience, only because if he were ever to have anything I thank God it’s this. Thank God it’s not cancer, or thank God it’s not, you know...I mean it really could be so much worse. If we keep working with him, I just have so much hope for the future that parents of other kids with disabilities don’t, and I am incredibly, incredibly fortunate, and I know that. And you know what, so what if he’s a little weird? I was a little weird. Have you noticed that I hardly make eye contact [laughing]?”

Near the end of the interview Dawn talked about her hopes for her children. “I hope my younger son will be unfettered by a label, and the older one will have a label but I hope he appears to be unfettered by a label to others. That will be my goal, and you know there are so many other worse things that can happen. I’ll take this any day of the week. I’m the kind of girl who came from a family where chaos reigns supreme, so this fits in. This disability fits in with my life [laughing]! And that’s even possible to say you know!”

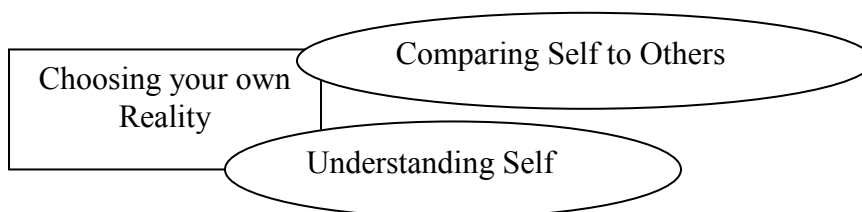
Professional Reflections

For me, Dawn represented another type of parent who chose her reality on life and her child’s disability, not only by comparing herself to others, but also by understanding her own strengths and weaknesses, and attempting to understand what type of disability “fit” into her life. It was very interesting to me that no matter what the disability was when each family decided to

choose a particular perspective they all felt that their situation was easier, better than anyone else's, and almost all made references to feeling "lucky" or "thankful" for issues that they felt they could deal with, and that would inspire personal growth.

While contemplating this idea with a colleague who also has a teenage son with a disability, she related that she did reach a point like this, where she would say she did "choose her own reality" but she said it took her quite a few years to get there. She related how after her son was born she would take walks around her neighborhood and cry, until one day it dawned on her that just because his life may not turn out as she had expected, it didn't mean he wouldn't have a happy life. This realization helped to move her forward to another place. These ideas led me to the concept of *choosing your own reality*.

Conceptual Category: Choosing your own Reality



One of the ways that parents seemed to create a picture for themselves and for their families was by choosing their own reality, or in other words making meaning of their child's disability. Much has been written about families "accepting" or "coping" or "adjusting" to having a child with a disability (Alston & Turner 1994; Blacher, 1984; Hodapp, Fidler & Smith, 1998; Klass, 1988; Linkowski, 1971; Linkowski, 1981; Miller, 1986). In the past, the stages of grieving (Kubler-Ross, 1969) have been used in an attempt to understand the emotions and actions of parents of children with disabilities. In this model acceptance is reached when parents "understand" their child's disability in the same way that professionals do. More recently, this

idea has been deemed as an oversimplification of the grief and acceptance process and others have attempted to move us toward a different understanding of acceptance.

Maris (1974) has argued that grief is linked to a loss of meaning, so for parents of a child with a disability they are placed in the unenviable position of making meaning of new rules and expectations while simultaneously attempting to find a purpose for their child's life and disability. The work of Olshansky (1962) and the concept of "chronic sorrow" has been discussed in recent years and the idea that parents of a child with a disability experience sorrow at various points in their lives, and that this sorrow ebbs and flows with life experiences. Featherstone (1980) has suggested that acceptance is an unreachable goal, and as families learn more about themselves, their child, and disability in conjunction with the inevitable changes that life provides to all of us, images that families hold about their lives and their children often change over time.

By realizing that grief and acceptance change and progress over time, it may be worthwhile for professionals to understand that helping a parent to "accept" a child's disability may not be as effective as supporting the family over time, and helping them to understand and cope with day to day issues along with concerns for the future. In order to do this offering a quick dose of support may not be the most beneficial path, but instead building trusting relationships may be more beneficial to families. For the parents I interviewed, they seemed to be in the process of consciously choosing a perspective. By doing this it seemed to me that they were attempting to make meaning for themselves related to having a child with a disability.

Zola (1995) provides support for the idea of parents having to make meaning of disability for themselves. He once wrote:

There is no special world of the disabled person, and herein lies a major problem...Most minority groups grow up in some special subculture, and thus form a series of norms and expectations; the physically disabled are not similarly prepared.

He was discussing his own situation as a man who had polio and who had survived a serious car accident, but was left with permanent debilitating reminders of his experiences. Zola shared how lacking a positive disability culture to identify with leaves one to forge one's own path. His words seem to be easily extended to the experiences of families that include a child with a disability.

Barnett, Clements, Kaplan-Estrin & Fialka (2003) have pointed out "the term acceptance implies an end point" (p. 187). I would argue that parents make meaning of their lives and through an ongoing process. Through talking to parents it seemed to me that they may choose to renavigate their view of their child's disability more than one time in their lives, depending on life events and circumstances. Bianca serves as an exemplar of a parent who compared herself and her children to others in order to help her to choose her own reality and make meaning of her experience, whereas Dawn seems to find meaning in the idea that one particular disability seems to fit into her life better than others.

Janet Vohs (1993) describes how this realization of choosing a path for herself and her daughter happened for her. She relates how when her daughter, Jessica, was one year old she was diagnosed with cerebral palsy. Until the diagnosis Janet had been "committed to having a life of joy" (p. 52). However, the diagnosis somehow translated to "a dark cloud or shadow under which I would have to live and with which I would have to cope" (p. 52). For some time she noticed herself feeling sad and her "immediate justification of the mood was 'Of course I am

sad, my daughter has cerebral palsy.”” But almost simultaneously she began asking herself exactly what was the matter?

Jessica was fine; she was a happy child who enjoyed playing, laughing, and babbling. Life in general was good, they had a home, food on the table, friends. No one was in pain and there was no visible reason to be feeling sad. At this moment, Janet says she began to cognitively separate how the disability was actually affecting life from how her interpretation of the disability was affecting life. She says that she began to think that maybe all of her emotional anguish wasn't necessary, and she began to define disability as a normal part of life. This helped her to shift her thoughts to more pertinent issues regarding Jessica.

In thinking about my experience as a practitioner, I began to feel that my personal ideas of disability and acceptance were about to be challenged. If by approaching disability in a different way would I be better able to support parents as they attempted to make meaning of the disability and choose their own reality? Choosing one's reality seems to be part of the process of meaning making. By making meaning of their child's disability in the ways discussed above, these parents appear to be implying that disability will only be a part of their lives and not the defining factor.

Additionally, they seem to be saying, “We can deal with this.” I would surmise that some parents do not make meaning in this way, and would perhaps view disability as having a much more negative impact on their families. However, because these families agreed to be interviewed about their lives and their children, I surmise that they may represent a group that view disability a bit more positively than other families who did not agree to be interviewed. By making meaning of disability in a positive way parents seemed to be beginning to carve out a niche for their child and themselves that may lead to a place of belonging.

Bianca's Story (Part II)

As you may recall Matt is a little over three years old and has been diagnosed with pervasive developmental disorder-not otherwise specified, or PDD-NOS. His safety is his family's biggest concern. They are also concerned with his seemingly unusual strength. He has pushed an adult friend across a room on a chair, has been able to push open doors being held closed by an adult, and has pulled a dresser down onto the floor. His parents have taken many unusual measures to keep him safe, including putting a lock on the outside of his bedroom door to use when he sleeps.

Bianca shared some of their struggles with Matt's behavior. "He has a lock on his bedroom door on the outside. If you had ever told me about a parent doing that I would have said that is child abuse but it keeps him safe. We have locks in other places too. One day when I was down in my studio rehearsing I heard a weird noise. I came upstairs and there was Matt on a chair by the sink with the garbage disposal on. I freaked out, I didn't scream but my heart was in my mouth for a week. So my husband put a special switch underneath the sink and I only run it every few days when he is not around so he doesn't see me and learn how to do it. Our family room is downstairs and we have a lock on that door so when we are downstairs I lock it and take the key and hide it. We spend a lot of time keeping him safe."

She talked again about getting the diagnosis for her son. "I totally didn't believe it because he is all about eye contact, and he is affectionate, and he doesn't have gauche body posture, he doesn't self stim. Which this other child we know who also has a diagnosis on the spectrum does and that drives me crazy." While talking about the period of time right after Matt was diagnosed with PDD-NOS she said, "And the other thing is too, even though I am not putting all my eggs in the basket, I am not expecting it, but I am hoping to cure it."

Bianca continued, “He is young enough that maybe we can get those neurons firing and those neural pathways going and maybe in two years...I said something to a friend about curing it and she asked, ‘What do you mean by that?’ I said, by curing I mean in two years you can take him to a developmental pediatrician and they would say ‘No diagnosis.’ So we are thinking he is going to lose his diagnosis...Hope to me would be Matt losing his diagnosis.”

Professional Reflections

Hope to me represents a very important but intangible aspect of life, but within the context of early intervention, hope initially seemed to me to be a way for parents to avoid reality. I felt that Bianca was focusing on one idea, a cure, which to me seemed unrealistic and maybe even dangerous. As an early interventionist my initial reaction to this type of thinking was that Bianca was perhaps a bit unrealistic and possibly even unwilling to face the future. But as I continued to interview, and in particular as I interviewed families that I knew from first-hand experience who in my opinion were loving and dedicated parents who were realistic and willing to face the future, this initial gut reaction did not sit well with me. As I continued to talk with parents, and as the issue of hope kept resurfacing in different ways, I was forced to re-examine my initial ideas.

Lynda and Lois' Story

Although I had worked with Bruce from when he was only a few months old to his third birthday and knew his medical history quite well, I hadn't seen him for almost two years. Therefore, I was unprepared for the little boy who greeted me when I arrived: a chubby, smiling four year old with glasses who was scooting across the floor toward a toy much faster than I anticipated! Also there to greet me were Bruce's twin sister Robin, his mom Lynda and

his grandmother Lois. Lois, Bruce's maternal grandmother, was often present when I had visited Bruce before he turned three, and remains an integral part of his life.

At the time of our meeting Bruce was attending a specialized private preschool that only accepts children with disabilities. In educational circles, this preschool would fall under the category of the most restrictive environment. However, Bruce's family is looking into an inclusive setting for him for next year. Bruce had brain surgery when he was eleven weeks old and still has some serious lingering effects from the surgery. He does not yet walk and was recently measured for an electric wheel chair. Although Bruce does not yet speak he currently knows and uses about 50 signs, recognizes colors, shapes, all of the letters of the alphabet, and can spell his name by pointing to the correct letters on a mat with the alphabet printed on it.

Bruce has a twin sister, Robin, who is typical. Lynda used to work full-time but recently quit her job in order to care for her children. Lynda has support from her husband and their large extended family that live in the area, including her mother, Lois.

We pick up the conversation when Lois, Bruce's grandmother, is talking about how she likes to go on-line and "talk" to other families whose children have had hemispherectomies. Lois began to share, "You read all about the kids that had the surgery six or seven months ago and..." Lynda finished her thought for her, "And they have unrealistic hopes."

"Well," said Lois, "so did we. That's how we used to think too. They write things like he looks normal. Lynda continued, "Yeah, but you don't break their spirits.

I think everyone is better off if you let parents think what they want, because our goals for Bruce might be unrealistic but you never really do know." Lois then vehemently said, "Yes, and I have a big problem with physical therapists, and occupational therapists, and teachers and everyone saying that. I mean *how do they know?* So unless they are God

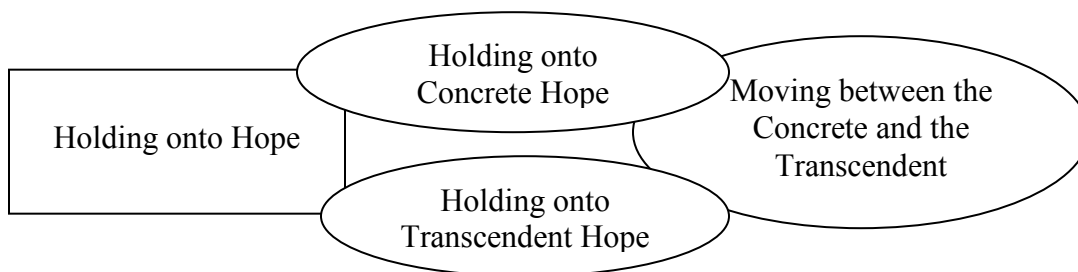
they cannot say what is unrealistic.”

Professional Reflections

During the course of the interview we talked about many things, but Lynda and Lois discussed hope in a way that was very intriguing to me. Although other families had talked about hope, Lynda and Lois helped me to deepen my thinking and understanding about its importance in relation to families of children with disabilities. In part, because listening to them talk about the extensiveness of Bruce’s medical care seemed to sit in such contrast with how they lived their life, and what they hoped for Bruce’s life.

This inner turmoil led me to the literature to explore how others were thinking about the concept of hope. I began to reframe my thinking on hope and parental expectations. Instead of assuming that mothers were being unrealistic, I began to view these paradoxical statements as parents attempting to successfully manage incongruent emotions (Larson, 1998). The ability to successfully manage these emotions may have a large impact on how families cope and deal with stress. Reading and reflecting on the concept of hope helped me to elucidate some of these issues and helped to lead me to my second conceptual category, *holding onto hope*.

Conceptual Category: Holding onto Hope



Barnard (1995), a medical doctor and ethicist at the University of Pittsburgh, defines hope as the ability “to project oneself beyond one’s present definition of reality, but with no guarantees against disappointment” (p. 48). However, hope is also elusive, complex, and

grounded in experience, therefore understanding it continues to evade researchers (Nekolaichuk, Jevne, & Maguire, 1999). Hope belongs to no single intellectual discipline and is claimed by many including philosophy, medicine, theology, psychology, and sociology (Barnard, 1995).

Smith and Sparkes (2005) have attempted to explore the concept of hope by describing three notions of hope that are common in Western cultures: concrete hope, transcendent hope, and despair or lack of hope. Although despair and a lack of hope have been linked to hope in some descriptions and definitions (Barnard, 1995; Tiger, 1999) the families that I interviewed did not talk about despair or a lack of hope. They may have despaired certain aspects of their situation, but no one expressed the idea that they had no hope for the present or the future. The fact that none of the parents I talked with discussed despair or lack of hope may in some way have to do with the young age of their children, or some other aspect of the lived experience of the parents I interviewed. Therefore, I have chosen to concentrate on two forms of hope that families discussed and that have been elucidated in the literature: concrete hope and transcendent hope. Bianca's comments seemed to symbolize a form of concrete hope.

Smith and Sparkes (2005) described concrete hope as the idea that today I am disabled but tomorrow I will be well again. Concrete hope is generally linked to a specific and observable outcome based on medical or technological advancements (Smith & Sparkes, 2005) such as a cure, or the mastery of a particular skill such as walking or talking. This idea is based in part on Marcel's (1962) thinking that concrete hope is oriented to particular results. Barnard (1995) utilizes a similar definition from the psychological literature of hope as a positive belief that a desirable outcome is possible.

Parents of children with disabilities, who have been interviewed by others for a variety of reasons, echo these ideas (Larson, 1998). Larson (1998) interviewed six mothers of Mexican

origin who have children with disabilities. Jescuita discussed her ten-year-old daughter who developed spastic quadriparesis after febrile seizures at age three.

I was living with the dream that she was going to jump off that [wheel] chair and go about her business. I am very patient...well, it's gonna happen. Now I am convinced it's not gonna be quite that way. It's gonna take a lot of little steps before that.

Other parents I met also talked about having very concrete hopes for their children such as eventually being “normal,” learning to talk, to walk and to behave appropriately through diet, nutrition, therapy and medical interventions. Zola (1982), who acquired a disability as a young man, shared his thoughts on concrete hope although he did not name it as such, “... almost all share deep within ourselves the hope for a miracle to reverse the process, a new drug or operation which will return us to a life of validity” (p. 206). For some holding onto hope for a cure seems to be helpful, others though, such as Lynda and her family often hope for less specific outcomes.

According to Smith and Sparkes (2005) those that hope transcendently emphasize their ability to reconstruct a new self, even though aspects of that new self may be presently unknown to the hoper, they demonstrate an openness to change, and a readiness to examine possibilities as they emerge. By extending Smith and Sparkes explanation of transcendent hope from individuals to families we see by not committing themselves solely to one outcome tied to a cure these families are free to explore the plethora of unknown and unforeseen possibilities that may arise.

The term transcendence is frequently associated with existentialist philosophy. Although it is outside the realm of this paper, and my expertise to discuss existentialism in any depth, for the purposes of this paper, I interpret the concept of transcendence to represent the possibility of human nature. In other words, transcendence is the idea that facts alone are unable to

definitively determine what human beings are capable of achieving. Extending this concept to the idea of hope leads us to the idea of transcendent hope.

Transcendent hope, as defined by Marcel (1962) is not oriented to a particular result such as a cure, as concrete hope is, but instead embraces uncertainty, celebrates surprise and is open to change. Barnard (1995) discussed how rather than being characterized by particular objectives, transcendent hope is repeatedly open to the suggestion that reality will at some point reveal presently unidentified sources of meaning and worth. With transcendent hope, exactly what is requested for may never be completely clear (Frank, 1995), but there is an underlying assumption that something is to be gained from the experience (Smith & Sparkes, 2005).

Smith and Sparkes (2005) interviewed fourteen men who had been paralyzed by playing sports. David, who is twenty-eight and works as a teaching assistant, was paralyzed playing rugby at the age of seventeen. He discusses hopeful notions of his future, “Hope for me now is about having opportunities, living in a better society which respects disabled people and values them, and not feeling tied down to one life plan” (p. 1099).

Having unspecific hopes seem to help people reframe and reinterpret their expectations for what the future may hold for themselves or for their children. Smith and Sparkes (2005) theorized that the men in their study who relied on transcendent hope were able to open themselves up to other ways of being. Their ability to do this helped the men to place the past behind them, live life in the present, and view the future as a landscape of possibility. Lynda seems to share this idea as she talks about parents of children who recently underwent hemispherectomies. “Well, eventually you hope they will start living one day at a time like we do now, because then you can eventually adjust to the future” and whatever that may hold.

Hope, however, is a fluid concept, and families often do not stay firmly rooted in one place of hope or another, but instead move between them.

Families also seemed to talk about moving back and forth between concrete and transcendent hope. In Bianca's case, at this point in time, she is hoping to cure her son of PDD-NOS. However, as we neared the end of the interview she said, "I don't know yet, if he doesn't lose his diagnosis, how this will manifest for him." She also talked at one point about hoping for a cure but "not putting all of her eggs in one basket." She seems to realize that hoping solely for her son to lose his diagnosis may not come to fruition, and by acknowledging this doubt; she is opening herself up to other possibilities.

Lynda and Lois both discussed how no one could predict what Bruce will be able to achieve in his future endeavors. However, in addition to keeping themselves open to a variety of possibilities, they also hold onto concrete hope. Lynda stated, "We knew that there was a good chance that things were not going to be normal, but even now I still hope that he will be normal.... Who knows? Maybe in time he will be normal. Some of these kids do, they go to college. We have heard of a couple who had had the surgery when they were older, and they say you do better if you have the surgery younger, and they are going to college...so who knows? ...It is the same surgery, and Bruce is more behind because he has been through a lot, but my hopes, what keeps me motivated in life is thinking he will walk and talk." Given Bruce's serious diagnosis I was surprised that his family hoped that one day he would be "normal." However, this comment seemed to help solidify my understanding a bit of how families are continually moving from one form of hope to another and back.

It is important to understand, as Barnard (1995), Taylor (1983) and others (Taylor & Brown, 1988; Smith & Sparkes, 2005) have pointed out that holding onto hope differs from

being unrealistic. Taylor (1983) interviewed a number of women with breast cancer. She found that the women who appeared to be coping the best had idealistically positive observations about their situations. Taylor commented that these women seemed to be sustained by illusion. Illusion, as many of us would define it, does not seem to fit into a healthy psychological framework for anyone facing a catastrophic illness or disability. Taylor, however, makes a vital distinction between illusion, and repression and denial. Taylor defines repression and denial as the altering of reality. Illusion, on the other hand, is a reinterpretation of reality. In Barnard's (1995) words people who operate under the idea of illusion are "giving themselves the benefit of the doubt;" they take the facts of their situations and utilize the uncertain nature of life to allow explanations of reality that remain within adaptive boundaries.

As I previously discussed, I initially felt that parents who held onto hope for their children might be acting unrealistically. However, I came to realize that hoping for a positive outcome for the future may not only be beneficial emotionally to the families, but it also seemed to help them to understand their experiences in a way that provided them with some meaning for their lives. Additionally, Barnard (1995) explains that by hoping you move into unknown territory as you try to create a new version of yourself.

When one hopes, one accepts the risks that moving "away from familiar stories and pictures, we must exist in a period of transition wherein we recognize the inapplicability of the old story, but have not yet become convinced of the coherence or direction of the new one" (p. 50, Barnard, 1995). To hope is to move away from the recognizable and the known while not yet understanding what is to come. As Vohs (1993) pointed out "having a vision is not just planning for the a future we already know how to get to. It is daring to dream about what is possible" (p. 63). Many of the parents I interviewed spoke about hope but discussed its nuances in different

ways. I came to believe that for these families having the ability to hold onto hope was a significant concept.

Parents seem to face this unknown with a mix of trepidation and a desire to find a means to begin to create new vision for their lives. One way it seems that parents begin to create a new vision of their family life is by recognizing their child's strengths. They also want others to recognize their child's unique strengths and positive attributes. Mary Kate shares her story.

Mary Kate's Story

Mary Kate's daughter, Susan, has been diagnosed with autism. According to Mary Kate Susan loves going to school and interacts with peers at school and in her neighborhood. She is a "master imitator" and has many wonderful skills, such as the ability to dress herself, she can independently zip her coat, color between the lines, and count to fifty. Mary Kate said, "any skill that relies on her memory is a definite strength for her." But she can also sometimes get aggressive without really meaning to; Mary Kate says that Susan often doesn't realize the consequences of her actions.

For example, a boy on the playground recently kicked Susan and she retaliated. However, she then saw "the beauty of the kick" as her mother describes it, and experimented with kicking for the next six months. Additionally, Susan's gross motor skills are excellent, and she is very adept at playground and climbing equipment. Mary Kate also shared that Susan doesn't always understand danger and has in the past wandered off on her own in stores or at the local swimming pool. Susan is presently taking ballet and swimming lessons.

Mary Kate is a married mother of two young children who works full-time as an attorney for a large prestigious private university. Prior to her work as a lawyer in academic circles, she was employed by a well-known law firm in the city where she put in many "billable" hours. Her

five and a half year old son Cooper attends kindergarten in the public school system, and her daughter Susan who was almost four years old at the time of the interview, attends a private, typical preschool.

Mary Kate discussed her decision to enroll Susan in a typical preschool where she is the only student with a disability and some of the unforeseen issues that have come up at school. “Well, I think it was the best decision we ever made; per my discussion with you remember [laughing]? I was not nervous because she had the TSS. Plus Cooper went there so I was familiar with the school. It’s a Catholic school, and I don’t think the administration is unfriendly to the whole situation. They knew she had some issues, and they were willing to give it a try. But some things were ridiculous, like pulling teeth. They set some bizarre rules.”

“For example, if her TSS isn’t there she is not allowed to be in the classroom, which might be understandable if I weren’t willing to sit outside the classroom in the hall on a bench for the entire class. A few months ago the TSS called off and I didn’t get the message until my mom had already taken her to school...and I had to go and pull her out screaming and crying with a ‘Oops, we’re not going to school today after all.’ And they never told me this rule; the problem is they have no knowledge, and in fact they are ignorant, and I don’t mean that in the rude sense, but in the uneducated sense.

“They are completely clueless. She’s groundbreaking in a sense. And this has happened more than once...but the last time I said I am not taking this anymore and I asked them to tell me the reason. They said it was liability issue. So I said, ‘Good, I will waive liability, send me the form.’ Then they said it wouldn’t happen again so we’ll have to see.” Mary Kate continued the discussion by talking about her reaction to the school situation.

“As bad as I want to punch or yell at the administration, Susan likes the school, she has friends, the teachers are very nice, and the TSS has assured me that the classroom is good. So I thought, I am not going to let my emotions get ahead of her. But it did make me so mad that I pulled Cooper and he is now at the public school. But he can make it on his own, so as mad as I am over the administration’s treatment of her, I am not going to affect her.”

Mary Kate also talked about her decision to discontinue early intervention services. “Well, we did have a person going in for about a month, but I was not seeing the benefits. ... They [the EI service provider] wanted to have another person go into the school to give advice, to consult. But at this school, these people don’t want advice; they don’t want to be bothered. They really don’t care about Susan, they want to get through the day, and then somehow it is a good program. They [the preschool] behaved so badly that I wasn’t open to another person. I wasn’t going to put more fuel on the fire. I wasn’t open; I don’t want it to be any more different than it is already.”

“I mean, you can’t rock the boat too much, or they’ll say no or this is too much trouble. ... I was the treasurer [at the school] when my son had been there I mean I was doing so much, it was like, “Go ahead and tell me no.” If I hadn’t been involved [at the school] it [Susan attending] wouldn’t have happened, it wouldn’t have happened. ... I don’t want her to be there if she’s not having fun. But if you don’t have a thick skin it’s a problem.”

Professional Reflections

Listening to Mary Kate talk about how she struggled and advocated for her daughter was interesting to me for a variety of reasons. Mary Kate is an attorney by trade, and in my experiences with her and her daughter, Mary Kate has been outspoken on many issues. Yet I felt that Mary Kate was struggling in a more passive way than I would have originally expected.

Why I wondered was this the case? I examined other interviews in an attempt to expand my understanding. I began to theorize that parents maybe chose one style over another in an attempt to mediate risk for their children. I began to view Mary Kate as a parent who passively struggled and advocated because she believed that path would lessen the risks to her daughter. Lara and Dan provided me with another viewpoint.

Lara and Dan's Story

I had worked with Lara, Dan and their son Paul for about a year and a half before Paul turned three. Paul had a diagnosis on the autism spectrum of PDD-NOS (pervasive developmental disorder-not otherwise specified). During the time I had worked with Paul, Lara and Dan had both utilized their flexible work schedules to take turns being home for my visits. Therefore, I felt I knew both of them fairly well. Their other son Danny was also often present during home visits so I also had a relationship with him. I was looking forward to seeing them all again. I interviewed them on a beautiful summer day. When I arrived both Lara and Dan were present, as were the two boys. They invited me to their back porch to sit and Lara brought out a large pitcher of iced tea.

They filled me in on what had been going on with them. "Well," Lara stated, "Danny is now six years old and goes to kindergarten. Paul is almost five and had been going to the early intervention pre-school program for the past two years. In the fall he will begin attending a typical pre-school program with therapeutic support staff (TSS). He is still crazy active and is a great runner, climber and loves to swim. He enjoys riding his bike and roller-skating!"

Lara is a nurse and converses easily in the language of special educators. She continued, "He still has issues with communication, but is improving each day. He uses simple phrases to communicate. He will parallel play with peers. He knows his colors, shapes and the letters of

the alphabet. He does not yet have a clear concept of danger and will sometimes act before thinking and he still has difficulty complying with adult directed activities. You know, he was eligible to attend kindergarten beginning in the fall, but we opted to keep him in early intervention for one more year. We think it will be beneficial for him.” Not too far into the interview Paul’s parents talked about what the IEP process was like for them.

Dan shared, “One of the things that is always devastating for us is to see is the evaluations for the IEP. Because we step back and we see how far he’s come in say the last six months, and on paper he may have only come a month, but it seems like so much more to us and like he’s developed so much more.” His wife Lara added, “It hurts.” “Yeah,” Dan continued, “it really drags you down.”

“I mean we’re thinking,” Lara added, “We’re thinking, Oh, he’s made so much progress. But then you see the IEP and he’s still only testing at a two year old level. It would be nice once in awhile on paper to see that he made a jump. ...But I’ll tell you he *has* made such progress, it used to be that going out to eat even was crazy. One of us would go in and order and the other would walk around outside with him or stay in the car. Then we’d hurry up and eat and leave. We were like, ‘I’ll be damned if you are going to not let us go out to eat!’ [Laughing]. I used to have to bring loads of toys to help keep him entertained, and now he’ll tell the lady - I want chicken and French fries and milk.” “Right,” agreed Dan nodding his head. “And now you can drop him off at the baby sitting center at the grocery store and he will stay there while we shop.”

Lara also shared how she and Dan felt it was important for others in the community to learn about Paul, and how they felt educating others would help Paul and lessen some of his risk in social situations. “A new family moved into the neighborhood and I went over to talk to the kids because I have talked to all the other kids in the neighborhood about Paul and they know he

doesn't always understand. So when I went to talk to the new kids, they were like, "We know, he's autistic, the other kids told us" and they all took off running (laughing). I am hoping that the parents will be cool and let him play. I know those kids are their children and they want the best for them, and I understand that, but I hope they will be willing to and open to let them play with Paul.

Lara continued with comments about friendships and their decision to move Paul to an inclusive school setting. She hopes that the preschool staff at Paul's new preschool takes the initiative to educate the children and parents about autism before Paul starts. "Before he goes [to preschool] I want to find out if the staff at his EI placement goes and talks to the parents. I am going to find that out, because I do want that. I'm afraid the parents won't let their kids interact with Paul. I think most kids are gonna be ok with him, unless he starts freaking out or screaming or something. But even then I think the next day the kids would probably go back to playing with him.... But it's more the parents than anything else. The parents are my biggest fear."

Lara and Dan seem to look at activities where others can learn as lessening the overall risk for their child, even though others may view the activities they choose as full of risk. One specific example is Lara and Dan's choice to allow Paul to participate in an Autism Week event at a local school. Lara shares her story. "My sister is a teacher and last week we went to her school as part of Autism Week, and she took him as 'show and tell' [laughter] to show that autistic kids are normal looking kids. And I was explaining stuff like eye contact and of course he did the opposite! Like going up to kids' desks and saying, 'Hi, how are you?' And then I said kids with autism don't always talk too much and he says, 'Paul has the hiccups' and he starts hiccupping and they all started laughing so he was a big clown."

Lara also talked about how she felt sharing with others and being open about her son, lessened not only the risks for her Paul, but for their family and everyone else involved in Paul's life. "We have a friend and their son was diagnosed last year with PDD and she still hasn't told her family or friends. In a way I think she's fine with the diagnosis, but she must not be so fine because she's not willing to talk about it. I think the less people that know the harder it's gonna be on her in the long run. ...I think it's more work up front but in the long run it's easier. ... She asked me why I talk to people and I want to make sure people know and be aware and look out for Paul. ...I mean that is support for her too if people know."

At one point in the interview Lara discussed a suggestion she had given the social worker at Paul's preschool about how and when the teacher's communicate with the parents, which has been a frustration for her throughout the school year. Lara thought it would be helpful to have a meeting with the teachers and interested parents so they could all sit down and talk about what the parents were looking for from the teachers, and conversely what the teachers would like from the parents. She was surprised that her idea was not well received. She continued discussing how she was not ready to give up on her idea just yet because she felt it would help not only Paul, but other children as well.

"Well, I will talk to the director and see what happens. [Laughing] Tomorrow we are going to a breakfast for the school's national organization, and we are the representatives from Western PA. We were chosen to represent them for the past year, but our reign is almost over so I need to talk to some people. I think it can only benefit people. I mean how can we help Paul and the other kids? I am definitely not shy about telling people about him, or autism, or what I have learned. There are so many people I have known or have met that their kids have recently been diagnosed and I love talking about it and telling them where to go, because no one

told us. And I love giving them a starting point and telling them what worked and didn't work for us. I really love it. I wish I had more time to do it."

Professional Reflections

When Lara and Dan talked about the IEP process I thought about how it was unfortunate that there was often no time and no formal place on the IEP to discuss strengths and progress that can't be measured by a standardized test, like the ability to go out to a restaurant and enjoy dinner with your family. However, improvement in day-to-day life issues seems to have a large impact on a family's quality of life. I began to think about how being able to go to a restaurant or the grocery store helps not only the child with a disability to maybe feel a sense of belonging, but also the family. Being able to participate in normal life activities seems to boost parental confidence and emotional well-being. Lara and Dan seem to be disappointed that professional staff at Paul's school didn't seem to recognize Paul's successes and strengths.

Their personal experiences seem to support some professional ideas. Rudolph and Epstein (2000) have commented that when it comes to assessment many teachers have been trained to identify deficits in the child's development. "Unfortunately, practitioners can become stuck in their view of the child and the family because they have too much information about the problem and not enough information about strengths and solutions" (p. 207). Additionally, by focusing on deficits practitioners may limit information families receive and may also put undue stress on the negative aspects of a child's behavior (Epstein, Harniss, Pearson, & Ryser, 1999). Without realizing it, by continually focusing on what Paul couldn't do had I added stress to Lara and Dan's life? Had I provided them with information that was helpful? Were there other ways in which I could have supported them that I never contemplated?

Additionally, Lara discussed how she and her husband, Dan, felt it was important to educate not only themselves but also others about their child's disability. Lara shared how they felt it was essential for others in the community to learn about Paul, and how they felt educating others would help Paul and lessen some of his risk in social situations. They seem to look at activities where others can learn as lessening the overall risk for their child, even though others may view the activities they choose as full of risk. Although they talked about educating *others* these measures appear to benefit Lara and Dan as well. As Emerson said, "It is one of the most beautiful compensations of life, that no man can sincerely try to help another without helping himself."

Lara and Dan seem unafraid to speak their minds and to push for things that may be seen as risky to some, although they seem to view the risks as being beneficial in the end for their child and family. Other parents also talked about struggling for services and other supports for their children with disabilities, in a different manner. Bonnie talks about life with her son Caden.

Bonnie's Story

I had previously worked with Caden so I already knew his mother, Bonnie. Bonnie works part-time as a hair stylist at an upscale urban salon. Her husband, Declan is in law enforcement. In addition to Caden, who is three and has been diagnosed with PDD-NOS, Bonnie and Declan also have a daughter, Eva. Eva is a typical five-year old who was getting ready to start kindergarten. Bonnie started the interview off by talking about Caden's progress. "He is still not talking, but has been learning to use pictures to communicate and some single words. He has been going to a private preschool program with other children who are on the spectrum. I think there is one little girl there who does not have a form of autism, but her twin brother goes so she goes too. Caden has been going for about three months, five days a week for

three hours a day. Next year we might send him in the afternoons too. They have a social program in the afternoons so we might do it. He doesn't really play yet but he has started to pay attention to other kids and when we go to the park he will watch them play."

"He is also beginning to mimic what other kids are doing. He still has excellent gross motor skills and can run, jump and climb with ease! He still flaps his hand and likes to watch the lights sometimes too, and he has started to act aggressively on occasion. I don't think he really understands that he may hurt someone though. When I tell him no he doesn't seem to get it. He really enjoys going to school and has adapted really well. Remember how worried we were and we almost didn't send him? He really likes it!"

When Bonnie mentioned her previous worries about pre-school I began to remember their anxiety. Because Bonnie and her family live within the city limits, when Caden turned three he was eligible to attend a fully funded early intervention pre-school program in the city. However, the programs that Caden qualified for were located at the opposite end of the city from where they live. He would have had to ride a bus both ways for almost an hour each way.

Bonnie was concerned that because children were bussed in from all over the city he wouldn't meet any local children. Declan was concerned that both schools the district gave them as educational options were located in high crime areas. Both he and his wife were uncomfortable putting their three-year-old son, who is non-verbal, on a bus for a lengthy ride and sending him to an area that they did not consider safe. Therefore, his family opted not to send him and they instead chose a local, private specialized pre-school program. His family pays out of pocket for his tuition. He does not have an IEP because his school placement is private. He does have a TSS that goes to school with him and helps out at home.

Near the end of the interview Bonnie talked at length about her relationship with her son's TSS. "The wrap-around system has been horrible for us. I am so frustrated and this is my son's life. ...I have to carry over a lot of things and I have her [Eva], and a house, and I feel like I am not doing anything right. I'm not giving her enough attention, I'm not educated enough for him [Caden], I'm not a good enough wife. ... I want people to work with him who will care about him. They don't have to fall in love with him, but I want them to be interested in him and trying to help him. ... They [TSS workers] come in and say, 'Well, let's just let him play today.' And I am not assertive enough. ... It has been so inconsistent, she calls off a lot, and we've had some problems.

I mean we went to the park and she would just push him in the swing and we have a behavior plan that has lots of communication stuff, using PECS [picture exchange system used to teach children to communicate], responding to yes and no. I mean when we go to the park I sometimes just let him swing too, but her job is to help him with other things and she doesn't do that at all. ... I am always supposed to come up with things and I mean am I going to have to school to figure out what's right for my son? ...I got to a certain point, I let it go for a while...and finally I said something, I made some suggestions. I mean I want them to know I am complaining. It's weird."

Bonnie also talked about enrolling Caden in a community sports activity when he got older and his current interactions with other children in the community. "I would like to get him into sports. I think I will do the community thing and just explain to people. I don't think they are allowed to discriminate against him so hopefully we can do it. I hope Declan will coach so that will make it easier... I am trying to stay positive in that area, but I just don't know yet. ...We don't have any kids in the neighborhood and I don't like that."

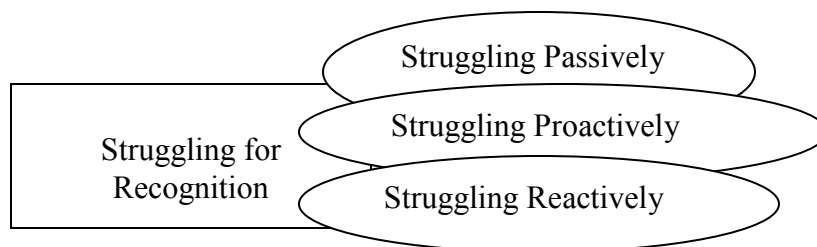
“We go to McDonald's and stuff. When you first look at him you can't tell that anything is wrong. He was pushing a little boy at McDonald's and I said to the mom, ‘Sorry, he has a form of autism.’ She was very nice, but we just left. ...I think he may have a challenge making friends, but if he goes to a typical school maybe people could explain about Caden. I want people to maybe explain why he’s backward or odd.”

Professional Reflections

Bonnie seems to move between struggling in a more passive manner and struggling proactively depending on the details of the situation. She acts passively because she doesn’t want to risk alienating herself or her son from the people who work with him, but when she feels that her passive stance begins to harm her son she begins to struggle more proactively on his behalf. Bonnie anticipates getting her son involved in community sports activities and is hoping that he will be allowed to participate. She also seems to feel that if her husband coaches that may lessen the risks to Caden. Additionally, when confronted with Caden’s differences she chooses not to educate others personally; however, she hopes that someone else will fulfill that role and educate Caden’s potential classmates about autism.

Initially I coded what parents were describing to me as advocating, and while I do still feel that parents are advocating for their children, by changing the code to struggling it seemed to capture more of what was happening. In my experience the word “advocating” carries with it connotations of power and control as parental advocating is typically associated with a fight to get more services, which usually costs the school district more money. These stories and ideas led me to the concept of *struggling for recognition*.

Conceptual Category: Struggling for Recognition



As previously stated, I initially coded these struggles as “advocating for one’s child” but as I began to really examine what parents were saying to me, it seemed that although they were advocating by definition, they were also struggling for a variety of things in a variety of ways. Mary Kate seemed to struggle passively, Lara and Dan seemed to struggle proactively, and Bonnie seemed to struggle reactively. I purposefully chose the word “struggle” as Webster’s dictionary defines struggle as “to make one’s way with difficulty” which seems to fit with what parents are attempting to do. I in no way feel that one method is better than any other. I feel that parents choose a method depending on what they feel will lessen risks, including social risks, to their children. By lessening risks, I think these parents feel they are increasing their child’s chances of finding a place to belong.

In fact, some parents view advocacy as being accompanied by risk to their children. Turnbull & Turnbull (2001) have found that family members often feel that by speaking up for their child, or by requesting what they want or need, professionals may retaliate. However, with risk exists possibility. One mother of a preschool child with Down syndrome talked (Nelson, 1995) of her journey to find an appropriate preschool for her child.

When Joey was almost two we began to think about a regular day care center. I thought any center would beg to accept my son in order to enrich the lives of the other children. Ten phone calls later I realized it wasn’t that simple. Most were not interested in “the challenge” and others promised to call back but never did. Finally I called the area director of the Discovery Schools. ... I waited for the inevitable silence, but instead I was assured they would be happy to accept Joey.

...As Joey moved from infant to toddler class we watched him bloom. ...Last September, at the age of four he advanced to the preschool class. ...One day I arrived to pick Joey up, but first stopped at his cubby to collect his things. There, under the day's artwork, lay a small white envelope. Heart pounding, I opened it to find an invitation to a classmate's birthday party. Outside I found Joey climbing the monkey bars with two other boys. He greeted me, then motioned enthusiastically to his companions. "Friends, Mommy. Friends" (p. 32).

For the special educational system to work well, parents and educators need to work together, but parents seem to assume that parent-professional partnerships are not truly equal, and this imbalance of power can be detrimental to successful working relationships. Blue-Banning et al. (2004) has surmised that an inequality of power in the relationships between parents and professionals is a major obstacle to creating successful partnerships. Others (Allen & Petr, 1996; Harry, Rueda, & Kalyanpur, 1999; Kirk, 2001; Turnbull & Turnbull, 2001) agree and indicate a central challenge in the development of true parent-professional collaboration is the failure to establish trusting relationships.

Through interviewing families, I began to see advocating as a struggle for, among other things, positive recognition of their children. Instead of viewing parents who advocate as "rocking the boat" but as attempting to "struggle" or make one's way with difficulty maybe we can move toward more equal parent-professional relationships. The teamwork that follows may lead to more trusting relationships, which may help to provide appropriate and caring individualized solutions to complex problems and issues. Turnbull and Turnbull (1997) noted the importance of building a trusting and relationship with family members:

When you have trusting and respectful relationships with families, you can practically ensure that collaboration and empowerment will be enhanced. By the same token, when families trust professionals, they create opportunities for all sorts of otherwise unattainable results (p. 73).

Additionally, Lara and Dan's frustration with a lack of progress noted on their son's IEP led me to think about how we recognize not only children's unique strengths, but also progress

and skills not measured by standardized tests that affect how families' live their lives. By recognizing strengths and progress not necessarily recognized on an IEP, we seem to signal to families that we see and value what each individual can achieve, and we are willing to support their efforts.

Dijkers (1996) discussed how on average people with disabilities seem to be less satisfied and happy with their lives if only objective measures are used. However, he cautions that one should not interpret these differences to mean that people with disabilities have lower satisfaction with their lives. This is because there is a lack of subjective well-being measures, and very little knowledge of how more objective measures relate to subjective qualities.

Pain, Dunn, Anderson, Darrah and Kratochvil (1998) identified dimensions of day-to-day living that helped people to feel satisfied and happy with their lives. Through focus group discussions Pain et al. talked to fifty-two participants that included adults with disabilities, and families of children with disabilities. Pain and her colleagues included families of children with disabilities as she posited that life satisfaction and emotional well-being are complicated within a pediatric context when the focus is typically not on the functioning and well being of a single individual, but the entire family.

They identified seven dimensions that they felt had an impact on individual and family life satisfaction including relationships, the ability to maximize one's potential, and the ability to have an enjoyable/meaningful life. Among other things, their analysis revealed that the satisfaction of any one family member influenced the satisfaction and happiness of the others. This consideration of satisfaction and happiness within a pediatric context seems to be consistent with the early intervention field's philosophy of striving for family-centered practices.

The participants of the focus groups in the Pain et al. (1998) included twenty-two parents of children with disabilities including language, behavior, physical and psychiatric issues; eighteen adults with disabilities that included brain injuries, spinal cord injuries, amputees or who were victims of a stroke; and twelve family members of the adults with disabilities. They reported remarkable similarities from this diverse group as to how the participants viewed positive aspects of their lives. Almost all of the participants talked about having hope, witnessing progress, maintaining a positive attitude, and having confidence in the future.

One of the other major findings of the study concerned attitudes expressed by the participants regarding maximizing their potential. These participants did not use “normal” as their sole frame of reference. This idea is contrary to medical professionals, who tend to equate high life satisfaction with normal functioning. Additionally, early intervention professionals (myself included) seem to spend a lot of time working on children’s deficits in our quest to help them reach goals often based on typical developmental milestones instead of truly individualizing educational plans. Striving for “normalcy” may not be a desired or appropriate goal for many children with disabilities and their families. Indeed, one parent shares her thoughts on using “normalcy” as the measuring stick for success, “the message to me as a mother that was pervasive in early intervention’s emphasis on developmental milestones was that we needed to “fix” James (Turnbull, Blue-Banning, Turbiville, & Park, 1999).

The one issue that I found particularly compelling through interviewing parents, was the parents’ struggle for someone to recognize that their child had value; that their child could succeed in a typical classroom, or could succeed in a community-sporting program; in essence, that their child belonged. Vohs (1993) described belonging as finding a place in the world where disability is not viewed as tragic, and where one is accepted for whom one is including

individual flaws and strengths. By reframing advocating as struggling, it seems to signal the inherent risks and uncertainty in the process. One of the things that the parents I interviewed seemed to struggle with was how to have others recognize their children's unique strengths. It appeared to me that for the parents I spoke with, recognition by others of the unique characteristics of their children was interpreted as a tacit acknowledgment that their child has a right to belong. Parents seem to approach this issue in a variety of ways.

Annie's Story

At the time of our interview I had never met Annie before or either of her two sons. Nate was five years old and Clay was three. Nate was involved in the early intervention system when he was younger due to speech and language and fine motor delays. Nate will soon be starting kindergarten in a typical, suburban classroom. He still receives support services in the form of private tutoring and occupational therapy for social issues and fine motor delays. Clay has a diagnosis of autism. Clay was attending a specialized early intervention classroom three days a week and a typical preschool program two days a week. Clay uses some single words but does not yet communicate in phrases or sentences. He thrives on structure and typically prefers to play alone, but will interact for short periods of time with familiar people.

Annie is a middle school teacher in a large suburban district and she told me on the phone when we were setting up the interview, "Because I am a teacher and a mother I really felt it was important to talk to you. I think social relationships are so important." When I arrived Annie began sharing some background information on her family. "My pediatrician continually suggested from very early on, that I should take Clay to a developmental pediatrician for an evaluation. I kept asking 'Why' and the pediatrician kept giving me vague answers. But

eventually I made the appointment. I later learned that my pediatrician has a son with autism and so I suspect that she was especially tuned in to Clay's delays."

Annie shared that while she was filling out the paperwork for the evaluation and providing developmental information to the clinicians, she began to realize that her son would probably be diagnosed with autism. "I am a teacher, we use rating scales and stuff at school, so as I answered questions I was getting an idea of where this was going. At his first appointment, because he was young, he wasn't diagnosed with anything, but at the follow-up appointment six months later he received a provisional diagnosis of autism, and three months after that he was officially diagnosed with autism. Then we began discrete trial training and became involved with home wrap around support services and early intervention."

Annie talked about the variety of difficulties she encountered when attempting to enroll Clay in activities to help him to make connections with typical children. First she talked about getting him into a typical preschool program. "You know it's funny how things work out. Nate, my older son, went to this same preschool and both he and I loved his teachers. When I signed Clay up the director called and said he would have the same teachers. I was so excited. But then the director called back and said the teachers said their room was too small to have the TSS. So I said, Well, we won't send the TSS. And then I finally got it when the director said, 'Annie, they won't take him.' I was upset, but they make no money and I guess they can say what they will or won't put up with when you get paid hardly anything. But then it did work out because the class they put him in happened to have a teacher who has a Master's in Special Education. I was so happy."

She shared that she felt something positive came out of his attending the typical preschool, which may lead to more positive things for his future. "Before school started I said

to my Mom, ‘I hope that he finds a friend’ and he did, so I love that he has a friend! ...Like say his friend Hannah from the typical preschool, maybe someday she will own a business and she may have some job he can do. But if he is tucked away somewhere and no one will ever know him and he won’t know anyone. If he’s never exposed to other kids, that’s not good. I mean if he doesn’t know, he may be happy just staying alone.”

Annie discussed some difficulties in getting the local Y, where her family has had a family membership for years, and difficulties with Clay’s therapeutic support staff to help her enroll and engage him in a community soccer league. “Before Clay was allowed to play we had to sign some forms about liability, and the TSS had to provide them with new criminal clearances, which I think is against the law to have her update them when hers were still good. And then we had to get proof of some other kind of insurance, and the TSS is not allowed to talk to any other kids or parents, and we weren’t allowed to work on any goals other than recreation. And then the TSS kept bringing Clay over to me because he was crying, but he didn’t want me, he wanted to get out of what he was doing. Well, the TSS wasn’t willing, but I hate to lay total blame on them, because ultimately Clay is the one who can’t do what everyone else is doing.

“...It would be easy to blame the TSS, and I almost said, ‘Don’t come’ to them at one point, but that is their job and they are paid to be there and I didn’t want them to lose money or hours either. And finally the coach said, ‘Why don’t you stand over here with him.’ So I did, but it’s sad sometimes because all the other moms are sitting and chit-chatting and I am over there talking to the coach or standing on the field. ...So just yesterday I said to the coach, ‘You know yesterday you said ‘ready, set, go’ and that is what we practiced, but today you said, ‘one, two, three’ and so I tried to talk to her about consistency, and she is trying, but I think they are

high school or college kids, so I have been trying to modify the program to meet his needs, but I would hate to officially say that because we had all those issues.

“And the BSC (behavior support counselor) didn’t want us to do the program, but it was important to me. ...She kept questioning that if I wanted him to learn how to kick a soccer ball she could work on that with him in the back yard. But how will he ever learn to be with regular kids if he never does it? You know if Nate weren’t playing in the same league I probably would have let Clay quit. I still don’t think they understand why I wanted to do it. I can’t even say why I wanted to do it.”

Annie also talked about the kinds of things she does at home with her boys. “I often invite kids over from the neighborhood to come and play and I usually have some type of structured activity, my kids need structure (laughing), and I will sit at the table with them doing a craft or something...”

Professional Reflections

Annie seems to be fulfilling many roles in order to help her son to make social connections. In the short time that I talked to her she discussed how she had taken on a variety of roles, although she did not name them as such. I, however, see her, in addition to being a mother, as taking on the role of advocate, administrative assistant, regular education teacher, special education teacher, and host to other neighborhood children. She has pushed to have her son included in both his neighborhood preschool and community sporting activities, she has looked into the legality of issues, she has gathered paperwork to comply with agency rules to have her son included, she has adapted the soccer program to help meet her sons needs, she has attempted to educate his soccer coach, she invites other children to her house to play, she organizes activities for them, and she participates in the activities. Annie seems to feel that by

taking on a variety of roles her son will benefit both now and potentially in the future. However, other parents approach things in a different manner. Mary Kate seems to feel that by allowing her daughter, Susan, to figure things out on her own, Susan will forge her own path of belonging.

Mary Kate's Story (Part II)

We met Mary Kate and Susan in a previous section. Mary Kate is an attorney and her daughter Susan has been diagnosed with autism. At one point during the interview Mary Kate began talking about her decision to sign Susan up for ballet and swimming lessons. "And with ballet and swimming, she does her own thing. In swimming she's doing fine. It's a group and she has to wait her turn and stuff. And I never said anything about her diagnoses, because I am right there so I can step in if something happens, and I just wanted her to muddle through and tow the line and follow the rules.

"She did swim away to the deep end a few times and I told the teacher and she has no fear, and they put a stop to it. She does recognize authority. Remember when you were still with us and she would wander away and just jump in the pool, no fear. She has maybe fifty percent fear now, but I just decided she will learn to swim. And well, my thoughts were I wanted to get her out there in the world. You know last year I tried it [swimming and dance] and it was a total disaster and this year she loves it!"

Mary Kate talked about her approach to Susan's level of participation in preschool activities. "Last month, the principal came to me and said that Susan was having a tantrum. And I said, 'Do you know why? Because you are letting her.' She recognizes authority and you have my permission to say, 'Knock it off.'" I told the teacher; so the past year we have tried to cut out all of the treat Susan differently stuff. For everyone else they say, 'It's time to make your duck'

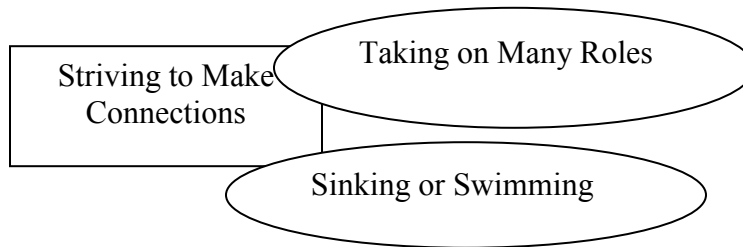
and then they come to Susan and say, ‘Susan, do you want to do your duck?’ I said, ‘No, Susan it’s time to do your duck.’ And she is doing it. I said treat her the same and it’s been working. “

Mary Kate shared her memories of the transition process from home-based services to preschool services. “She doesn’t have an IEP because the IEP was for a specialized program and I didn’t want that. I didn’t want her to be any more different than she has to be. They offered me the special program but I said ‘No way.’ I don’t even think I investigated a bunch of options because she was going to the preschool where Cooper went [laughing].”

Professional Reflections

In contrast to Annie, Mary Kate seems to take a very different approach when attempting to help her daughter make connections. She does not want Susan to be treated any differently than necessary, and seems to feel that many situations call for a sink or swim approach. She talked about signing Susan up for swimming and ballet the previous year and it not working, but she tried again the following year without discussing Susan’s diagnosis with the staff, and she feels Susan has been successful. I don’t think that one approach to making connections is any better than the other. Parents seem to use the approach that they feel will be the most beneficial to their child. These ideas led me to my fourth conceptual category, *striving to make connections*.

Conceptual Category: Striving to Make Connections



Barnard (1995) suggests that our relationships with others and a sense of connection to the wider social world help us to craft and attribute meaning to ourselves. Additionally, social development theorists (Erikson, 1963, 1968; Sullivan, 1953) believe that early social relationships are a necessary step in forming one's individual self-identity. Smith and Sparkes (2005) attest to the idea that when people find themselves in uncharted terrain due specifically to disability, one way they begin to form their own identity is by striving to make connections and building relationships with others. Through relationships with others we often learn about and define aspects of ourselves. These ideas are strikingly similar to Vohs' (1993) idea of belonging and the importance she places on having a sense that one belongs. I found that parents attempt to help foster a place of belonging for their children in different ways. One means seems to be by taking on many roles such as teacher, friend, coach in order to help their child make connections with others. Annie provided me a concrete example of taking on many roles, while Mary Kate's approach seems to be one of sink or swim.

For young children with disabilities their parents often strive to help them to make social connections. Participants in the Pain et al. (1998) study talked about the importance of relationships. Other researchers (Bach & MacDaniel, 1993; Engstrom & Nordeson, 1995), attempting to understand what helps to make people feel satisfied and happy with their lives,

have also identified relationships as a contributing factor to life satisfaction, including the importance of connecting with others.

Individuals who have participated in other studies concerning their overall satisfaction with life (MacPherson, 1996) often consider themselves to be highly satisfied and happy in spite of having severe impairments. Indeed, the World Health Organization's International Classification of Functioning, Disability and Health, also known as the ICF, (2001) recently focused on creating a new framework for assessing disability and the quality of one's life. The ICF classification system looks not only at an individual's body structure and impairments, but also at their activity level, participation and involvement in life, and environmental factors. Therefore, an individual may receive a high score related to his impairment level if he has a severe disability, however, that same individual may be a socially active and participating member of society with or without supports so that in spite of a serious impairment, his functional ability would also be quite high.

This ICF framework combines two major models of disability, the medical model which views disability as a feature of the person and calls for interventions and other treatments to "correct" the problem, and the social model which views disability as a socially created problem and calls for a political and societal response to disability in the form of changing unaccommodating physical and attitudinal barriers. In contrast, the ICF calls for a biopsychosocial model of disability, which provides an integration of medical and social issues and recognizes a more coherent view of the entire individual. This type of framework seems like it may be helpful to early intervention practitioners to understand and utilize when looking at the importance of relationships, among other life factors, for children with disabilities.

In addition to the plethora of previously discussed benefits of connecting with others to form social relationships, Rubin (2002) discussed that for typical children growing up today, they are consistently expected to be able to make social connections. In generations past children rarely got together with peers other than brothers and sisters and possibly cousins. Today, however, children as young as six months old participate in Mommy and Me classes, attend daycares and preschools, and play groups. Furthermore, according to Rubin (2002), children of this generation will participate in these types of activities longer than children have done at any other point in history.

Consequently, learning to get along with peers is a critical skill that starts earlier and lasts longer for this generation of children than any previous generation of children. It is therefore not surprising that parents are anxious about helping children attain and maintain this skill. As discussed previously in chapter two, parents of children with disabilities often feel the need to get more involved in their children's lives for a variety of reasons. If belonging is as important as Vohs (1993) purports it to be, maybe helping families to make connections in whatever way they feel comfortable doing may ultimately be as beneficial in supporting families as working on skill development. By choosing their own reality, holding onto hope, struggling for recognition, and striving to make connections parents seemed to be attempting to move their children toward a place of hope and belonging and away from social isolation. Moreover, parents seem to live with a constant sense of shifting pictures.

Glimpses into a Kaleidoscopic World

As I attempted to understand the view that parents held of their world, and the meanings they were making about parenting a child with a disability, I also began to notice a shift of my own understandings as a practitioner. Parents seemed to hold a variety of views about their lives,

and the combination of these views helped me to examine a shift in my own ideas about my practice.

The Wildly Shifting Picture

As Lynda and her mother Lois talked about the birth of Lynda's twins they recounted the excitement everyone was feeling when they found out she was pregnant. Lynda is the oldest of three children, and her siblings and parents were all anxiously awaiting the arrival of the first niece or nephew and grandchild. Although she had been very ill, she kept trying to work through it by focusing on becoming a mother. During a routine ultrasound at sixteen weeks, their excitement swelled to new proportions when she was told she was having twins, a boy and a girl, and that carrying two babies was probably some of the cause of her extreme nausea over the past few months. However, their excitement quickly gave way to more anxious feelings. Her husband and mother didn't even have time to fully extend their arms to cheer about the twins when they heard someone say, "There's something wrong with one of the babies, it looks like a brain abnormality, but I can't tell what."

A week later Lynda was again at the doctor's office with her mother, but this time they were visiting a specialist, who performed another ultra sound. He confirmed that there was a problem with the male baby's brain but he wasn't sure what it was. Every two weeks they went back to the specialist for another ultrasound and ever-changing diagnoses. One week it was, "agenesis of the corpus collosum," the next it was "hydrocephaly." Although the medical terminology was scary to them, the amount of fluid in her little boy's brain stayed the same week after week, which they were told was the best-case scenario. They allowed their worries to subside a bit. When he was born his APGAR scores were normal, and both family members and the doctor thought he looked "normal." Lynda recounted how she silently cheered, "Yes!" in her

head. But moments later he had a seizure, and then another, and soon he was moved to the NICU.

While in the NICU they performed many tests, had him on a variety of drugs, and they offered Lynda and her family a variety of diagnoses after settling on one -hemimegaencephaly, which for Bruce, the baby's new name, meant that the right side of his brain was abnormal and larger than the left side, and was causing seizures. At that point Lynda recalls how they told her, "Well he's probably going to be a vegetable and would have no quality of life." Her mom, Lois remembers, "they told us to take him home and love him..." The doctors put Bruce on Phenobarbital for his seizures, and Lynda says that she "still thought he would be normal." He looked okay, he wasn't having seizures, and no one really explained anything to her.

"By the time Bruce came home I had already been home for a week with a newborn, and we were trying to care for her in between running to the hospital constantly to see him, and the seizures were stopped because of the drugs, so when we brought him home I didn't think he was totally normal but that he could be. But then he started having seizures again, and we were running to the hospital and they would increase his meds, but it didn't help, and he was having hundreds of seizures of day. The people at the hospital told us he was on enough medication to sedate a horse, but it still wasn't stopping the seizures. That's when it started to dawn on me that we may be in for more than we initially thought. And at eleven weeks old they decided his only chance for survival was to have brain surgery, and so he had a hemispherectomy. You know, looking back, even during all of that I don't even think I knew it was real. I handled it well because it all happened so fast." Her mom agrees, "Yes, it was so fast, and so much was going on that we just dealt with it." Lynda says, "only when we were told that the halves of his brain had to be disconnected did it start to hit me how serious it was."

In order to save his life his brain was cut in two, leaving the abnormal half inside his skull but disconnected. In the past, the abnormal half of the brain was removed from the patient's skull, but in more recent years doctors have discovered that removing the non-functioning part of the brain leaves the normal half open to injury inside of the skull due to excessive movement within the skull cavity. While in the hospital he contracted spinal meningitis, which was treated, and a few weeks later he needed emergency surgery to put a shunt in his brain to help drain the fluid build-up. Lois, Bruce's grandmother, shares, "It's crazy, but even now five years later things still aren't settled because you don't have time to think and things are still happening all the time."

Since his brain surgery Bruce has had numerous other surgeries including eye surgery, ear surgery, the removal of his tonsils and adenoids, botox surgery, heel cord lengthening, and a double hip osteotomy. He also has two more surgeries scheduled for the near future: having a hole in his ear drum repaired and the removal of the metal plates in his hips. Lynda and Lois talked in detail about Bruce's most recent surgery, the double hip osteotomy.

Lois recalled, that it was "horrible" almost worse than the brain surgery. He was only in the hospital for three days and then he was released. Lynda told me how Bruce was bed-ridden for six weeks at home in a hospital bed that they had set up in his bedroom. He had a large foam pad between his legs, and the pad wasn't allowed to be moved. The pad proved to be a nightmare for Lynda as she had to sponge bathe him and change his diapers without adjusting the pad.

"Let me just tell you changing diapers was..." she trails off for a few minutes before starting again. "I didn't know how to move him, he had stitches everywhere, he wasn't allowed to move his legs, and I couldn't take the pad out. A nurse came once a day to check his

bandages, but other than that she wasn't any help. I hated it!" "Plus," Lois interjected, "he had heel cord lengthening at the same time so he had a cast on his left leg." Lynda insisted I go into another room of the house with her, where her computer was, to see pictures of Bruce right after his hip surgery. As I looked at the pictures with her, she shook her head seemingly remembering some of the details vividly once again, "It was so horrible," she murmured.

In spite of Bruce's many medical issues his family talks about taking him out to dinner, to the movies, to amusement parks (where he went on his first roller coaster ride), to the mall, and to the beach. They describe him as having a "very normal life." They share how teachers at Bruce's school have been delighted with him, in part because he is willing to try just about anything. Lois, Bruce's grandmother says, "He has such a good spirit, a good soul. His soul is good and pure and happy and nobody can change that."

Lois continues, "Well, you know, we try to look at the plusses, and you gotta think about is he physically behind, he most certainly is. He doesn't walk or talk, and if someone were telling me about an almost five year old that didn't walk or talk... However, he has come so far, and we feel he is intelligent so we have to weigh things, and if we could take our pick we would pick that he couldn't walk or talk [instead of difficulties socially or cognitively]. Now, does it sometimes pop into my mind, is he ever gonna walk or talk? Yes, but I just put it right back out because what good is that going to do and sit and think about that?" Lynda agrees stating, "There is no time to sit and think about how different he is from other kids. It's a fact of your life."

Less than two minutes later though Lynda seemed to have a change of heart about feeling that Bruce is different and said, "When I see other kids his age running around then it hits me. When we go to a picnic all of the kids are running around and me or my husband has to sit with Bruce, and as well as he is doing, it hits you, and you realize how different your life is." They

continued to converse about how he couldn't walk or talk and how they were okay with that because he had other wonderful skills, "It makes no difference to us and I just think maybe in the next few years he will walk or talk. But I am not sad. I mean cognitively he has come so far so if we could take our pick we would pick couldn't walk or talk."

Once again a few minutes later the conversation took another turn. Lynda was complaining in a friendly, daughterly way about how her mother, Lois, is always trying to make her feel better and how sometimes that makes her mad because there are some days she just doesn't want her mother cheering her up. But Lois interjects, "Well, that is my job as a mother to try to make you feel better, I am sad too, but that is my job." "But Mom," Lynda practically shouts, "it's not that great, he's not walking or talking and there are other kids with the same surgery and they can do stuff and it makes me mad that he gets it all. It makes me really mad." Lois shakes her head in agreement and says softly, "She's right he gets it all."

Discussion about Bruce's needs led to Lynda and Lois chatting with me about where he goes to school. "Well right now he is in a specialized school and that is safe, he will never get made fun of. One good thing maybe that he looks different so it's kind of good in a way, because maybe kids won't tease him because they see that something is very different about him. That is definitely a fear, that he will get teased, I really try not to think about it." Lois agrees and says, "Yes, my husband and I, as grandparents, that is our greatest fear too, that he will get teased." And then moments later Lynda commented, "Well, we want him to be in a typical school, because if he stays in the special school he would be secluded and sheltered, and he will never know what the real world is like. If I keep him at that school he will never get teased. Never. But, well everybody gets teased."

Professional Reflections

There is no doubt that Bruce has made great strides in the past five years. He attends a specialized school, can point to colors and numbers on request, and is beginning to use the toilet. However, he cannot yet walk or talk and it is obvious that he is different from your average five-year-old boy. I had known Bruce's family for five years, but I wasn't here as an early intervention teacher or as a friend, I was here to interview them for a research paper. As the conversation went on Lynda and Lois continued to quickly change the direction of the conversation and it left me feeling a bit unbalanced. What could I make of these paradoxical statements?

Initially I was a bit unsettled as they talked about how crudely the doctor conveyed his opinion that Bruce would be a "vegetable." While I don't agree with his method, I had a hard time understanding that if a medical professional gives you news like that, how you leave the hospital hoping for "normal?" I left their home figuratively scratching my head. What did they really mean? I had worked with them for three years from the time of Bruce's surgery until he turned three, and I had always thought of them as totally together and on top of their lives and Bruce's care. I had always looked forward to visiting them each week, and in addition to the fact that I enjoyed working with Bruce I also enjoyed the company of his family.

As time went on I began to consider them not just as clients but also as friends and I would like to think they felt the same about me. I had talked about them anonymously in classes and during presentations. They had presented jointly with me in a variety of courses that I taught or guest lectured for at a local university. Could I have been wrong about my initial assessment of them? Were they barely holding it together? Wildly shifting statements and emotions from one moment to the next in the interview context didn't seem very stable to me. I

began to wonder if they were unwilling to face some hard truths about Bruce, and for some reason this made me feel sad for them and for myself.

Subtly Shifting Picture

Carolyn lives in a well-maintained suburban home in an upscale neighborhood. She used to work as a middle-school teacher but left the profession long ago to be a stay a home mother. She is married and has two daughters, Kate and Jennifer. Kate is going into second grade and Jennifer will soon be six and entering kindergarten. Carolyn met me at her front door and invited me into her house. We walked past the living room where I noticed some beautiful and unique black and white pictures of two young girls hanging on the wall. Carolyn noticed me looking at the pictures and said, “Oh those are the girls. My husband took those. It’s kind of a hobby for him. For those pictures he had them make faces –scary, silly and smiling and then he grouped them together. They are nice aren’t they?” I agreed that they were lovely pictures and commented that although I didn’t know the girls, the pictures seemed to capture a bit of their personalities more than a typical posed portrait would. She smiled and nodded her head and invited me into her dining room asking if I wanted anything to drink.

Once we were settled into chairs she began to tell me her story. They had recently moved from another state thousands of miles from here and so far they were quite pleased with the relocation. Because I had never met her daughter, Jennifer, I asked her to describe her for me. “Well, I had her evaluated because she has bizarre gestures that have evolved. Maybe bizarre isn’t the right word. Unusual. I always thought the things she did were kind of strange. But at the same time she is a delightful, happy and well-adjusted.” After she was evaluated Jennifer was diagnosed with developmental delay and began attending a specialized preschool in the mornings and a typical preschool in the afternoons. She will be attending her neighborhood

school in the fall with speech services once a week, and occupational therapy services on a consultant and as needed basis.

Carolyn talked about how since they were not originally from the area her children didn't have any family close-by, which set them apart from many of the other neighborhood children, who seemed to be constantly playing with cousins and other extended family members. Until recently, most of Jennifer's social contacts came through school. Carolyn elaborated, "Well, she is a quiet kid, but she made a couple of friends. There was one girl she really liked and they played. But I think Jennifer was more of a periphery person and she didn't really have any close friendships...." Carolyn described her mixed feelings about Jennifer's future relationships. "I don't have any concerns. Well, she hasn't had a best friend but she has had people to play with so I have a feeling she will find someone, hmm...well I hope she does. I guess I am not overly confident but cautiously optimistic."

After talking a bit more how she hoped Jennifer would find a friend, Carolyn had this to say, "Well, a new family just moved in up the street and they have a little girl so she and Jennifer have been thick as thieves. That is probably the closest she has had to a best friend. But that little girl is on the precocious side and I am wondering if she will outgrow Jennifer? But it has been really nice. So I am hopeful. Hopeful that she will have more friends, but I don't care if she, I don't want to say goes through friends, but kind of tries out different people. You know how some kids have "the friend" and if "the friend" is away on vacation or something your world falls apart. So I think it will be okay."

Carolyn continued to talk about Jennifer's personality and what this may mean for the future as far as relationships go. "Well, she doesn't have to be in the full fray to enjoy herself. She is happy to be a spectator. But I would feel badly if she were overlooked and not included.

I am OK with her being on the quieter side. I mean I would like her to be social, but maybe that comes later. At least I know that she won't be in detention for talking or something else. One kid at her school is always talking and others joined in but Jennifer stayed on task. So that's the good that comes out of it."

Professional Reflections

As Carolyn talked I made a mental note that she seemed to be preparing herself for a range of acceptable friendships for her daughter by talking out loud about all of the possible types of friendships that would be acceptable to her as a parent. It was great that her daughter had a best friend, she was hopeful she would have more good friends, but if she didn't have a best friend that would be okay too. We talked and laughed a bit about how you take the good with the bad with kids, but once again after the interview as I went back and looked over the transcriptions I wondered what was going on here?

Carolyn felt it was okay if her daughter was quiet, but Carolyn would feel bad if by being quiet Jennifer were overlooked. She wants Jennifer to be social, but it's okay if she's not social because she will stay on task and not into trouble for talking to peers at school. I later saw that Carolyn also shared some inconsistent statements about Jennifer's personality. "You can't push her. She will stand up for herself so I am not worried about that, she is not a lemming." Yet then she said, "she is really, she really likes to follow the program so I think school will be very agreeable to her."

What did Carolyn see in her daughter? What did she want for her daughter? She didn't seem to be sure. It seemed to me that she was seeing subtly shifting views of her daughter, and these changing views were maybe helping to move her to place of meaning and understanding. She seemed to delicately move between and among statements, that indicated to me that the

picture of her daughter's strengths and needs was somewhat solidified in her head, but the picture still had a tendency to be unstable at times. Was this what Bruce's family had been doing also - thinking aloud to help sort out all of the shifting ideas that swirl around in your head? Although due to his medical conditions his family's views seemed to shift much more dramatically than Carolyn's. As a parent myself I could relate to talking aloud through issues, and sometimes vacillating between extremes about what was best for my son. I began to view these changing statements in a new but unsure light.

Attempting to Hold the Picture Steady

I had worked with Bonnie's son Caden from the time he was eighteen months old to his third birthday. When I first starting working with him he had not yet received a diagnosis of PDD-NOS (pervasive developmental disorder-not otherwise specified). Bonnie remembered that time in her life. "He wasn't engaging at all when he was a toddler. He had limited eye contact, he would rock excessively in his exersaucer and at first we thought it was cute. But then I noticed some hand flapping. Our pediatrician said he was fine, but I called early intervention." One of Bonnie's best friends has a son who has autism so she was familiar with the system. "Once I called everything started happening at once, occupational therapy, speech therapy, physical therapy, and then you came as our teacher. A few months after that he was diagnosed."

She continued to talk about what it was like when he was diagnosed as having a disability on the autism spectrum. "I was suspecting autism but I had never heard of PDD-NOS. I was devastated but I wasn't surprised." I remembered back to when Caden was diagnosed. Bonnie asked a lot of questions and I remember that she would often search on-line for answers and information. She shared, "I just tried to find some success stories. I tried to find other mothers who had kids on the spectrum, and I looked on-line which wasn't good all the time because I

heard some bad stuff. And I took anti-depressants,” she said as she laughed. Her laughter seemed to me to be part nervous and part relief as she looked back on what was obviously a very difficult time in her life.

Bonnie went on to say, “You know you go through your couple months of devastation and then you realize it might be ok. Well, I talked to the therapists a lot too.” She started to share her thoughts on Caden’s and her concerns about the future. “Right now my main concern is communication, communication and then social skills. I don’t think he is missing that part right now. When he starts to say to me I wish I had a friend then I will push that and try to get him together with other kids. I hope he misses that at some point, because if he were oblivious to it that would be a problem, if he just didn’t care. Because I don’t want him to feel alone.”

Along with Bonnie’s idea that Caden is not yet missing friends she talked about time constraints when thinking about helping him to foster friendships. “We haven’t done any gymboree or swimming or anything yet. Right now we have so much school and therapy that I don’t even know when we do it. I also want him to be able to follow directions before we get him into something. Maybe t-ball, but he needs to get his receptive and expressive language a little more up to par before we start something.”

Bonnie talked about Caden’s sister, Eva, and the interactions between the two of them. “I think she is good for him. She chases him around and forces him to interact. He seems to enjoy begin with other kids. I think I am just trying to stay positive that he will do well in that area, but I just don’t know yet. For the future it’s a big concern, I don’t want him to feel alone, but I also want him to feel like himself. I don’t want him to have change who he is.” She shared how the neighborhood they lived in didn’t have many kids around, but she tried to get together with families that have children who attend Caden’s school.

“We have play-groups with kids from school every once in awhile at someone’s house. We take turns. It goes good. Well, the kids are all on the spectrum so they are all kind of doing their own thing. It’s not like they play hide and seek or anything. They’re together but...At school they try to get the kids to interact as much as possible and they play games and stuff. I think he may have a challenge making friends. I think it will be my responsibility and maybe the school’s but I don’t know how anyone can make somebody have a friend.”

Bonnie talked a bit more about what the future may hold as far as friendships go for Caden. “It’s been pretty good for now. All of my friends know what’s going on, but I think as he gets older I will get a better sense of which kids are nice and which kids are mean. I’ll have to cross that bridge when we come to it. I want him to have a friend with a disability because I would want him to someone around who is like him, so he doesn’t feel alone. And I want him to have typical friends too. Anyone who would be a friend to him.”

Although Bonnie felt that Eva was a good role model for Caden, she said she often wondered about Eva and how to talk about Caden to her. When I used to work with Caden I always got a big kick out of Eva. She was a very precocious five year old who always wanted to be involved, sometimes monopolizing the play in a jubilant five year old way. When I would arrive she would often be waiting at the door with questions and requests to wear my bracelets or use my pens and paper. Sometimes Bonnie would try to distract Eva during sessions, but more often than not we just included her as she seemed to enjoy participating in whatever was going on with her brother.

However, Bonnie talked about some of her concerns for Eva. “Eva asks a lot of questions, and her friend Haley and Caden are the same age and she always asks, ‘Why is Haley talking and Caden isn’t?’ Stuff like that. I just tell her that boys are a little bit behind but he’ll

catch up. I just don't want to explain autism to her right now. She is going to his preschool this summer as a typical peer and there will be another little girl there who is typical so they can play. I told Eva she will be the helper for Caden and she can help the teacher so she is really pumped up. I wanted her to do something fun with Caden, something for the both of them."

Talking about Eva seemed to pave the way for Bonnie to make some comparisons between her children. "I hope and pray he will be able to make friends. For his own self-esteem and because he will see Eva have friends and other kids have friends. " Bonnie got a little misty eyed as she continued, "I want him to know that he is accepted for who he is...I just don't know, I don't know. I know it will be different for Eva and him, I mean Eva has already had little preschool friends call her on the phone. I don't think it will come as natural to him."

Bonnie talked about getting together with other mothers who had children diagnosed with forms of autism. "I talk to other mothers and they say their kids don't have friends, but they are ok, it's the mothers who are upset. The kids seem just as happy playing on the computer. If it comes to that then I want what will make him happy. I am not going to force him to have friends, if he's uncomfortable, then I'll wait. I only want to intervene so much."

Professional Reflections

While I interviewed Bonnie, Caden played nearby and continuously put cars in and out of a toy house. Bonnie seemed to talk about her expectations for the future but she kept commenting that things would have to wait until he was more talkative, or could follow directions, or was able to communicate what he wanted. She seemed to me to be attempting to keep the status quo until something shifted somewhere that may force her to make a move in a particular direction. From a strict interventionist viewpoint I would consider Bonnie to be doing

well. She has some obvious concerns for the future, but nothing that seems to be out of the ordinary or immediately pressing. Everything seems to be going well, and maybe it is.

However, even though Bonnie appeared to be doing well, there seemed to be things that she would have liked some help with and although she didn't get into specifics. At the very end of the interview she said to me, "I wish I could pay out of pocket for someone like you to come back. ... You can't hire someone like you, and you usually don't find out that something is going on with your kids until they are around two or even later so you only have a year of home stuff. That piece is missing and wrap-around services don't fill the gap." Unfortunately, without the time for families to talk and professionals to listen it would be difficult to ascertain what would be helpful to families who seem to be gazing at a steady view.

When I had worked with Caden it had been a tumultuous time in Bonnie's life. Looking back I felt I did a good job in supporting her through his diagnosis. At the end of the interview she made a comment about how she missed all of us, because she didn't feel she presently had very much professional support. However, I began to wonder if I were working with Caden now would I be able to be supportive? As a practitioner it is often easy to be helpful around a turbulent time. There are obvious things to do and say.

However, supporting families as they are attempting to maintain their view seems as if it may be more difficult. Perhaps in part because of both time and professional constraints, by meeting with families for one hour a week over a period of time it often takes months to build the kind of relationship where the family is comfortable enough to begin to share concerns other than goal related concerns, and when a comfortable and trusting relationship is finally forged, it is often time for the family to move on to other services and providers. Additionally, having the

freedom to sit and only listen to the parent without working with the child is often not a professional option.

Different Pictures

Bianca greeted me at her door with a firm handshake. When she spoke she had a familiar accent and I asked where she was from originally. “New York,” she answered as she continued to pump my hand up and down. “Come on in, Matt is sleeping and Jade is with a friend so we have some uninterrupted time. Do you want a cappuccino? I am making one for myself.” “Sure,” I replied. As she strode into her kitchen, with me trailing behind, she seemed to fit my stereotype of a native New Yorker: confident, to the point, and walking with a purpose. Once we were settled with our cappuccinos in front of us she got down to business and talked to me about herself and her family.

Bianca shared that she was a singer and musician and sometime composer. She played a variety of instruments including guitar and piano, and music played a very important part in her life. Her daughter was already taking piano lessons and she hoped that her son would someday show an interest in music also. “Right now, he’s still young, but soon I am going to get him started. You can always count on your music.” After a few moments of getting acquainted with her she began to talk about her son, Matt and how he received a diagnosis.

“I have a friend in the special ed field and she thought Matt had some odd behaviors. To make a long story short he was diagnosed shortly before his third birthday with pervasive developmental disorder – not otherwise specified, or PDD-NOS. He’s three and a half now, and his sister Jade is six.” Currently, Matt attends a specialized preschool in her neighborhood. Bianca talked about not being a native to the city and how that had been difficult for her because it seemed to her that everyone that lived in her neighborhood had done so for generations and

they all seem to have many social connections already. She shared that she and her husband participated in some social activities through her church where she was quite active.

As the discussion turned to friendships she talked about some of the difficulties her son had particularly with social relationships, as that is part of his diagnosis. However, she didn't seem to see a big relationship between his diagnosis and his current disinterest in friendships. "I think that it is more about the fact that he is a boy and I believe that he doesn't need a friend right now. He's young. But I do see that changing. I do also see him going to regular elementary school and I see issues arising that have nothing to do with his PDD, like me not being able to be there with him." As Bianca continued to talk about friendships for her son she shared that he was having his first real birthday in a few months.

"We will probably rent the pony and everything," she said as she laughed. "It's so worth it just to see a horse in your back yard and at first kids freak out and after awhile they are like back to playing with Tupperware! I don't know who we will invite yet. Matt only mentions two kids from school who ride the bus with him, but I don't think it's right just to invite two. I don't like that. I like everybody. I need to see the composition of the classes. I have been thinking about it though. It really concerns me to invite the kids from his school because I have seen them in group settings and a couple of them scream, but then I don't want to not include them, so I don't know what I am going to do. I know that many people, my husband included, don't do well seeing children with disabilities. He gets very sad and freaked out, and you can't just say 'Hey, this isn't about you, deal with it, this is this child's reality.' I don't think Matt will miss anyone in particular as long as there is cake and ice cream, and presents and a pony."

Professional Reflections

I found it very interesting that Bianca didn't seem to identify Matt as having a disability and she didn't seem to see him as similar to other children at his school. However, he was attending a specialized preschool and he had a medical diagnosis on the autism spectrum. Additionally, she had talked very candidly throughout the interview about her son's difficulties such as running away from her in public because he didn't understand danger, of being so strong that he had pulled furniture down on himself, and of having to lock him in his room to keep him safe. These ideas seemed almost diametrically opposed to me.

Before completing these family interviews, and before I had time to reflect on these shifting images and statements from parents, I think I would have quickly assumed that she was being unrealistic, or not accepting of her son's disability. I began to wonder if I had her son as a student, prior to doing this grounded theory study, would I have inwardly rolled my eyes as she talked and thought to myself "Well, she will soon see what I see; she will someday know the truth about her son." Would I have tried to "help" her and push her to be more "accepting" by bringing her articles on PDD-NOS? I began to cringe at my own self-righteousness.

Sharing the Picture

Mary Kate was one of only two parents that opted not to meet at her home. I think she was happy to have a few hours away from her kids and her husband. I had worked with her daughter Susan for about a year and a half both before and after she was diagnosed with autism. When I worked with her daughter, I often found myself staying at Mary Kate's house after the visit was officially over chatting with her. We had many things in common, including knowing several mutual acquaintances. I always enjoyed working with Susan and visiting with Mary Kate. When she suggested I interview her at a local coffee house, it seemed more like meeting

with an old friend than collecting text for my dissertation. Mary Kate started talking about how Susan was diagnosed.

“Well, I always thought she was a bit behind, because she was my second child, but I know you shouldn’t compare kids so I just ignored it for a while.” Mary Kate explained how she was working a fifty to sixty hour workweek, so she chalked Susan’s delays up to being the second child, and decided to keep an eye on her development. She noted that she “put it on my list of things to do.” But a month or so later Mary Kate took Susan to a local park to meet a friend and her son who at fourteen months of age was around the same age as Susan. They were feeding the ducks and her friend’s son was quacking like a duck, and pointing to things, and Mary Kate began to think “Whoa! He is not that advanced.” She began to contemplate her daughter’s development once again.

So when Susan was around fifteen months old Mary Kate decided that she couldn’t ignore her instincts any longer. She made an appointment for her husband to take Susan to the pediatrician. Mary Kate told her husband to tell the pediatrician that she couldn’t quite put her finger on what if anything was wrong, but she had a feeling that something was not right. Susan was not yet speaking or pointing to things. At the appointment the pediatrician assured her husband that everything was fine.

A month later Mary Kate had the opportunity to observe Susan once again with some peers, and once again she felt that Susan’s behaviors seemed odd so she made another appointment with the pediatrician. This time she told the pediatrician that she did not want to hear that everything was all right. Susan and her parents were then referred to hearing and speech specialists. It was determined that her hearing was fine, but she was diagnosed with speech apraxia. The speech therapist also referred the family to a behavioral specialist. Mary

Kate was under the impression that a behavior specialist fell into the realm of psychiatric services so she cancelled the appointment. “Well, we floundered around a bit,” she said.

Although Mary Kate still “felt” that something more was going on with Susan, she was happy to receive a diagnosis of only speech delay and pushed the other thoughts from her head. The speech specialist suggested to Mary Kate that she request a developmental and behavioral assessment for Susan to try to find a few more answers. I was the developmental therapist called in to do the assessment. I remember working with Susan for about fifteen minutes and completing parts of the formal battery of tests when I recommended to Mary Kate that Susan receive developmental therapy services. Her eyes filled with tears and she said to me, “You can tell already that she needs help?” I remember feeling very badly that I had given her my professional opinion so quickly.

At twenty months of age Susan began receiving in home speech and developmental therapies. Both the speech therapist and myself suggested that Mary Kate look to a developmental pediatrician for a possible diagnosis. Mary Kate revealed that she always thought something was going on, but she kept going back and forth as to what it was, or maybe it wasn't anything. At one point, she remembered the speech therapist bringing up the word autism to her. Mary Kate talked to me about it at our next session and I also agreed that may be what was going on with Susan. Mary Kate talked about how she went to work the next day and didn't get anything done because she went on-line and researched autism, and was just “reading, reading, reading.”

Shortly thereafter Mary Kate made an appointment for Susan with a developmental pediatrician. Mary Kate revealed that the appointment was at the same place that she was initially referred to for Susan's behavior, but by this time Mary Kate said she was not surprised

with the diagnosis of autism. Mary Kate said she was satisfied with the delayed path they took, because she felt that Susan, now around two years old, would not have received a diagnosis had they gone earlier due to Susan's age at that time of less than eighteen months. Mary Kate said she wanted to know and didn't want to know, but in the end she thought that not wanting to know was silly. "In the end, I was forever grateful that those words came out of that person's mouth, because we would have continued to flounder. After reading about autism it was a lot different than I thought it was. I was still unsure, but I was thinking that my knowledge was wrong about the disorder."

Currently, Mary Kate says that Susan "talks up a storm," but her mother also reports that in spite of a fairly large vocabulary Susan doesn't really communicate well. She doesn't consistently react to others' comments or questions, and she doesn't seem to grasp the reciprocity of a conversation. Susan instead prefers to converse at her own pace and on topics that are of interest to her. Mary Kate feels that at the age of four Susan's peers do not seem to notice Susan's quirkiness, but that at some point her weak conversational skills may present some issues for Susan.

Susan attends a private preschool program where she is the only child with a disability. A full-time therapeutic support staff (TSS) aide attends school with her. Although Susan is eligible for other early intervention support services (developmental, and speech and language therapy) her family opted not to utilize those services at this point in time. Mary Kate discussed how she feels at some point they will "circle back around" to get services, probably speech, but for now they are satisfied with Susan's progress.

Mary Kate shared what she wanted for her daughter's future and how having choices was important to her. "Well, I just want her to be normal, and not in the, I don't care if she's quirky

sense, but in the she can get through life sense. I don't want her working in the Wal-Mart stockroom if she doesn't want to. If she wants to then I would support it, but if that's what she has to do I would be sad for her. I want her to be happy and capable of getting through life without needing help. I want her to be able to support herself whatever that meansI do always wonder though." Mary Kate started crying and takes a minute to compose herself before continuing.

Mary Kate talked about some of Susan's other difficulties, but then began to focus on her daughter's strengths. She felt her strengths were currently helping her to fit in at school and in the neighborhood. "I mean I totally see her making it. The thing that is helpful to her is she is very friendly. In terms of the 4 year olds, I would almost vote her the most popular." Mary Kate describes Susan as very dramatic and someone who always an entrance. When Mary Kate drops Susan off at school, she will often stand outside of the door to observe what happens. According to Mary Kate, when Susan walks into school she often announces her arrival in some way, by choosing one student and saying something like, "Hellooo, oh aren't you beautiful!" Or publicizing her entrance with "Surprise everyone, I'm here!"

She said frequently after Susan's arrival many of the other students yell, "Susan's here!" And then Susan will walk over to the table as the five girls gather around and Susan will say, "Let's play dolls" or give some other suggestion and more often than not the other girls agree. Mary Kate says, "So she is like one of the leaders. She doesn't come home and talk about the kids, but that is something she can't do. She has trouble with recall. The reason we know is that we have her 'shadower' [the TSS] that reports back to us. If I ask 'Who are your friends?' She can name those friends at school. She also has two friends in the neighborhood, they are also

four years old, and they have been heading down to our house to play.” Mary Kate finishes her thought laughing and saying, “So basically she has more friends than her brother!”

However, Mary Kate then talked about how in the future Susan’s sense of belonging may shift as others begin to notice she is different. “At four she can talk up a storm, but right now the other 4 year olds don’t notice that she is talking but she is not really communicating with anyone. No one has noticed that she’s a bit odd yet. In a couple of years they might notice. The kids don’t notice that she has a TSS; they just think she is another teacher. So for now she has been able to get through situations.”

Mary Kate expressed that at this point in time friends are about “a fifteen percent worry for me, where just a short time ago it was a one hundred percent worry, it was hideous. I mean every situation we were involved in there was a one hundred percent chance that there would be some hideous incident, but now there is about a fifty percent chance that there will be NO incident. All the kids play with her, but I always wonder though, will Cooper have to look for her?” Mary Kate started crying. “I am saving for college and I wonder will she be able to use it? Maybe we should save more for Cooper? You always just wonder, wonder, wonder. It’s a constant worry, but you just hope.”

Mary Kate regained her composure and continued, “she’s smart, and she can count to fifty and zipper her coat. She can do anything that is memory related. But who’s the worst conversationalist? Susan!” she responded as she laughed. “She always wins the coloring contests because you have to color in the lines, and she colors in the lines. But it is all a constant worry. If I didn’t have any hope it would be terrible.”

Professional Reflections

Meeting with Mary Kate brought back some memories for me about working with Susan. When I began working with her I felt that I had started our relationship off poorly by jumping into professional mode so quickly when I had assessed her. I often feel that it is a double-edged sword being called in for your “professional opinion.” Parents want an answer, that is why you are there, but it’s also very difficult to deliver bad news to parents, and often times you have just met the parents that day so you have no prior relationship with them at all.

In this case, I was the therapist chosen to also deliver services to Susan so I got to know them and they got to me. As I mentioned previously we had many things in common. As a matter of fact, Mary Kate reminded me of myself; and some days during therapy sessions we talked about our own lives as I worked with Susan. I really began to like and value my relationships with Mary Kate. So, when it was time for Susan’s annual re-evaluation I was hoping that her test scores would show that she had made some improvements, because I wanted to give Mary Kate better news than I had the first time I had tested Susan.

The day of the evaluation, Mary Kate and Susan, the speech therapist, myself, the service coordinator, and a student who was observing the service coordinator were all in attendance. As I completed my portions of the evaluation I realized that Susan had indeed improved her scores and in some areas she was actually scoring above her age level. I remember being inwardly elated. When it came time to report to the team Susan’s scores I got very choked up, as I listed her age equivalents. I saw Mom getting teary, and I had to look away because I felt like I was going to start crying in her living room. I thought I had myself together enough to continue, but when I started speaking again I caught Susan out of the corner of my eye, happily dancing around in her pink tutu to music that was playing on the television. I caught Mary Kate’s eye

also watching her daughter who was blissfully leaping and twirling, seemingly unaware of the group of adults sitting in her living room on her behalf. Mary Kate saw me and asked, “Are you crying?” For a moment I hesitated. I contemplated lying and telling her that something was in my eye, but in that instant I decided to be truthful. I silently shook my head yes.

Mary Kate got teary again; as did I while the other professionals sat and stared at us for a few seconds before we both started laughing. I remember being mortified at the time and thinking, “What in the world is wrong with me that I reacted like that?” I was worried that Mary Kate would see me as less professional, not to mention my other colleagues who were in the room with us. Within about thirty minutes the evaluation was over and we all gathered our belongings to leave. Mary Kate walked me to the door, and as I had one hand on the doorknob she leaned in and said, “Thank you for caring about my daughter.”

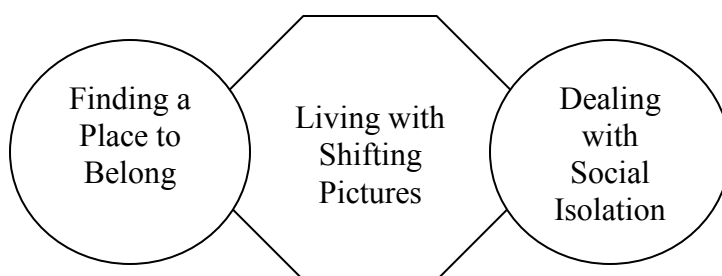
I mumbled a quick “you’re welcome, see you next week,” and almost ran out of the house. I got to my car and I think I cried halfway to my next client’s home. Although the episode would pop into my mind momentarily throughout the rest of the day, after a few more visits with other families it was already turning into a dim memory. By the end of the day I had decided to forget it, and had chalked it up to an embarrassing mistake that I would rather not revisit.

I am still not sure why I had such a strong emotional reaction that day. I have worked with other mothers who have been similar to me and I have forged working friendships with them. I have worked with other children whom I have desperately wanted to do well. I could go on and on and try to pinpoint what it was, but in the end I will probably never be sure.

However, I do think that part of the answer is this: I had let my professional guard down repeatedly during my visits with Mary Kate and Susan, and during those visits we had talked

about many of our hopes and concerns for our children and families. Therefore, during that evaluation in that moment I think I *truly understood* what Mary Kate wanted for her daughter, and it didn't necessarily have anything to do with improved test scores. In that moment I was probably professionally the best I had ever been as I had shared Mary Kate's view for one brief instant.

Core Concept – Living with Shifting Pictures



The vignettes above are representations of my five understandings of shifting pictures families may view. However, I do not feel that any family consistently views the same picture, although one picture may be more pleasing or dominant than another. Therefore, these views are fluid and readers may see pieces of other views in each vignette. Some pictures may shift within minutes, and then back again until each family member is able to create a picture that works for them in that moment. Some pictures may take months or years to shift. I have come to understand that for this small group of parents there seem to be five approaches to shifting pictures: wildly shifting pictures, subtly shifting pictures, attempting to hold the picture steady, different pictures and sharing the view.

I in no way assume that this is an exhaustive list of all the ways that parents make meaning of their experiences. However, approaching the ground in this manner has helped me to examine my practice on a level that I have previously not been able to do. I hope by discussing

these approaches other practitioners may see value in understanding family experience on a deeper level.

In our culture shifting views and fluctuating statements are typically not seen as a positive attribute. When individuals shift and contradict themselves, they are often said to be “talking out of both sides of their mouth” meaning they are at best untrustworthy and at worst liars. However, I have come to believe that for the families I interviewed the use of changing statements accompanied by seemingly fluctuating ideas is necessary in that these statements and ideas help families to sift through their own constantly shifting pictures and begin to help them make meaning of their experiences.

What I have come to appreciate is that although these pictures may be fleeting or long lasting they are purposeful, whether I as an early intervention teacher understand the purpose or not. Additionally, it seems it would behoove me as a practitioner to understand that these pictures exist and to respect families as I attempt to support them as they grapple with these shifts. By allowing families the space they need and the respect they deserve, I feel I can be a more empathetic and effective practitioner.

Families seem to view a variety of shifting pictures that change at different rates. Although shifting pictures represents my core concept, it is necessary to revisit Charmaz’s (2006) discussion referring to the appropriateness or fit of one core concept. Therefore, along with the core concept, it appeared that one of the reasons parents shift and want others to sometimes shift with them in order to see their view is to help move their children toward belonging and away from social isolation. Garrison (1987), in discussing Lachman’s work in the field of economics, said that the kaleidoscope metaphor captures the presence or absence of a tendency toward equilibrium in a market economy. However, I am applying this idea to families

who seem to be trying to capture the presence of equilibrium and symmetry (belonging) while simultaneously trying to avoid the absence of equilibrium and asymmetry (isolation). These ideas are discussed in depth in the following chapter.

Chapter 5: The Object Box Moving from the Ground to Theory

Chapter Purpose and Organization

The purpose of this chapter is to offer a theoretic perspective on what I learned from a small group of parents of children with disabilities. Therefore this chapter answers guiding question number four: What theory conveys my understanding of the meanings that parents make of their preschool children's social relationships when their child has a developmental disability? This theoretical portrayal has helped me to reach a deeper level of understanding of my practice and myself. I begin by explicating my core concept, shifting pictures. In addition I will discuss how through the constant process of viewing shifting pictures parents seem to be attempting to maintain symmetry or equilibrium for their children in the form of belonging. Simultaneously they seem to be attempting to avoid asymmetry or disequilibria in the form of social isolation.

Living with Shifting Pictures: Views through a Kaleidoscope

Through my teaching experience and immersion in the special education literature, I understood how multifaceted the issues were surrounding the social relationships of children with disabilities. However, as parents shared their stories with me about having a child with a disability, and more specifically what and how they thought about social relationships for their children, I began to understand on a deeper level how exceedingly complex social relationships are. Additionally, I noticed that as I was attempting to make meaning, it seemed that parents were also simultaneously attempting to make meaning. Initially, I saw this as a huge problem. I struggled for months and months with the question: How could I, as a novice researcher, understand how parents of children with disabilities make meaning of their children's social relationships, if the parents themselves were trying to make meaning?

However, at one point I began to think that maybe it wasn't an exact meaning or meanings that was important, but instead what was important for me to understand was that a constantly shifting and changing process of meaning making exists for parents. These parental views appear to shift depending on time and situational understandings, while the seemingly underlying goal for parents is to help their children to find some place of belonging, of community and of happiness. Parents of children with disabilities have talked about this shifting process of meaning-making without always naming it as such (Carnevale et al., 2006; LaSalle, 2003; Steele, 2000; Tetreau, 1995; Vohs, 1998). I began to envision a kaleidoscope.

All of the pieces inside the kaleidoscope are both similar and yet different, and perception can change with one small shift. None of the "pictures" in a kaleidoscope are more or less beautiful; it all depends on the eye of the beholder. I certainly don't think I have identified all of the pieces of the "social relationship" kaleidoscope, but the parts I have found intriguing may be intriguing to others, with room for other views and possibilities to be added, shared and discussed.

Lachmann (1976), an Austrian business scholar, quotes Shackle (1976) in his description of a "kaleidic world" as one that "intersperses moments of intervals and order, assurance and beauty with sudden disintegration" (p. 48) into something new. I think the dynamics of this metaphoric relationship captures parental meanings and understandings of having a child with a disability and wanting friends for that child quite eloquently.

The words of author Beth Nonte Russel (2004) help to summarize my thinking about both the positive and negative aspects about the shifting pictures parents experience:

The truth is that every single moment of every single life is uncertain. True power lies in accepting that everything is uncertain in every moment, it is where our freedom lies. A small shift in thinking and one can see that if everything is uncertain, then anything is possible (p. 165).

As a practitioner I have often been frustrated by parents seeming inability or disinterest in setting goals or following through with information that they have requested of me. However, by understanding that from week-to-week, month-to-month, sometimes even maybe day-to-day parental perspective is changing and shifting I feel I can be a more empathetic and supportive practitioner. As Goodnow (1999) contended when examining family issues it is important to move beyond “families matter” and move toward what matters to families. However, the idea of understanding what matters to families, and utilizing family centered practice is not always as easy as it may seem.

Dennis Tetreau (1995) is a school principal who has worked in the education field for over a decade. He is also the father of a son with special needs. He has acknowledged that even as a long-time public school employee, the special education system was often perplexing to navigate. The school didn’t always understand his parental priorities and concerns for his son, in part because he had a very difficult time expressing his expectations during school related meetings. He remembers feeling intimidated, anxious, worried, and confused. Mr. Tetreau’s experience helps to remind us that helping parents verbalize their goals and expectations for their children is not always as simplistic as we may think.

Furthermore, as early intervention practitioners it seems we are consistently oriented toward helping a child attain skills; skills that are specific, observable and measurable. Although, I feel social skills are indeed important, it also seems to me that parents may be contemplating a larger issue, and that is the idea of belonging, which often goes, as Vohs (1998) pointed out unnamed and unexamined. By understanding that the parental desire to help their children to belong coupled with a fear of social isolation is a constantly shifting issue that may

lie at the core of the parenting experience, I think I will be able to approach interventions from a different stance. A stance that I feel may open the door to as yet unknown possibilities.

As I initially set out to examine social relationships, and as the study evolved, it seemed to me that having a friend or friends in some way symbolized to parents a part of life that was “hopeful” and signaled to families that their child belonged. Successful social relationships for children with disabilities seemed to me to be a visual manifestation for parents that they were parenting their children well. However, parents seemed to me to be continually adjusting and readjusting how they attempted to make meaning of these experiences and the experiences of their children.

For purposes of this dissertation I chose to describe the ground beginning with the vignette entitled, *choosing your own reality*. However, this should not be interpreted as the starting point of the journey for all or even most families; some parents may begin their journey here and others may not. For example, if a child has been diagnosed in utero parents may have chosen their own reality long before the birth of their child, and they may move through this idea again at another time in their lives or maybe not at all, depending on life’s circumstances. Parents may move through, or in and out of these concepts in a variety of ways and at different times in their lives. Once again, the shifting and changing pictures and perspectives of a kaleidoscope seem apropos.

Therefore the four categories that I found to be particularly compelling: choosing your own reality, holding onto hope, struggling for recognition, and striving to make connections are all separate, and yet fluid and related, and don’t necessarily happen in a particular order. Parents seem to move back and forth between and among these conceptual places ultimately in search of

a place of belonging for their child. It is my impression that for parents social relationships are one observable sign that their child belongs.

Finding a Place to Belong and Dealing with Social Isolation

Vohs (1993) feels that “belonging” empowers people to feel they deserve to have choices that ultimately lead them to personal freedom; in whatever manner each individual defines freedom. This seems to be evidenced in part by Mary Kate’s poignant worry about her daughter working at the Wal-Mart stock room. Mary Kate was not worried that her daughter would work at a Wal-Mart, but that she would have to work there because she had no other options. The idea of having your choices limited because others have determined what your strengths and capabilities are or will be was an unsettling idea to me. I began to understand more clearly why the participants in the Lutz and Bowers (2005) study were so concerned with how others viewed them. Other people’s perceptions and recognition of strengths seems to have a much larger impact on people with disabilities than I originally imagined, in some cases having an impact on the basic human assumptions of belonging and freedom.

Vohs (1993) goes on to say:

I am convinced that the issue of belonging is at the heart of the considerable pain there is in relation to disability, and is probably close to the heart of what it is to be a human being today. Yet belonging is hardly ever acknowledged as an issue (p. 56).

Unfortunately, not all families are successful in their attempts to find a place of belonging for their child, which leads them to deal with social isolation.

Additionally, “belonging” and “isolation” - the idea of what they mean to parents seems to change over time. What some parents described as belonging or isolating behaviors and expectations at the age of three, may transform as their children grow and change and as the parents themselves grow and change. In essence ideas and desires that were once central may

still exist as time goes on, however, they may be modified or become more or less dominant. Just as all the pieces of glass remain inside the kaleidoscope, pieces that are central to each picture shift with movement and time.

In describing Lachman's (1976) view of a "kaleidic world" Garrison (1987) says, the pattern in the kaleidoscope has "order and beauty but not longevity. No given pattern can last for long" (p. 78). It is in this sense that I feel that parental meanings of belonging and social isolation can shift, and that as early interventionists we should be aware that this temporal and nuanced shifting seems to exist continually below the surface of observable actions. I would like to provide an example from Bianca. She shared how she hoped her son Matt would be able to make friends but if not he could always rely on his sister and his music.

Well, he has a sister. One of my nieces is an only child so friendships have been very, very important for her, but I think when you have a sibling that it is built-in and there is always someone around.

Later in the conversation Bianca said:

I hope our contacts now with people are setting the stage for later at age six or seven. I think then he would want a buddy. He would get bored and I couldn't fill that void. He wouldn't want me to ride bikes with him. I would have to orchestrate something for him. I tell him though if you have your music, your instruments will never let you down. If you are sad or lonely or confused you play. ...God and music won't let you down. If he and his sister form a band with two other kids they will have instant friends.

Bianca seems to be discussing the many perspectives of belonging. She hopes that her son will have "a buddy" that he can pal around with, but is also thankful that he will always have his sister to be a "built-in" friend. Furthermore, if he doesn't find a good friend, or tires of hanging out with his mother or sister, she hopes he will always have his music or faith in God. She seems to be preparing herself for the uncertainties of life and seems to make meaning not of

one idea of social relationships, but of a spectrum of shifting ideas on “what it means to belong” with different points on the spectrum being acceptable to her.

Annie, another parent I talked with, shared that both her family and her husband’s extended family live nearby which provides her sons with many opportunities to interact with their cousins, and how Clay seems to enjoy both going with and doing things with his cousins. However, she wondered, as he got older, because of his diagnosis of autism, would interacting with others remain important to him? She shared that if he began to lose interest in interacting with family and friends she would be upset, but she took some solace in the words of Temple Grandin.

I do see it as he would be missing out on something, but in Temple’s book she said she didn’t even miss that. ...Of course I would rather have a typical child, but in one of Temple’s books she says she would never change herself and even though I would change him, I hope he feels the same way Temple does about herself.

Here again, I feel that Annie is shifting her meanings of social relationships between what exists in the present while simultaneously attempting to positively make meaning of what may happen in the future. She hopes that Clay will continue to enjoy interacting with others, but if that hope does not come to fruition in the future, she hopes he will be happy with himself.

Nel Noddings (2003) has written extensively on happiness and education, and she discusses in depth the importance of community. She writes that happiness and community are intertwined and that by belonging to a community people gain recognition, which helps them to think positively about themselves and to be productive and thinking members of a larger society. When people do not feel they belong to a community she feels that melancholy and uneasiness may set in, which may lead to a general unexplained unhappiness. Noddings posits that, “many children suffer years of unhappiness because they are not accepted by peers, and are deprived of

that much-needed sense of belonging” (p. 222). She continues, “we all have a need to belong, but for some of us this need is satisfied so easily that we fail to recognize either the need or the satisfaction” (p. 222).

This quote from Noddings brings to mind a metaphor that Vohs (1993) used. As I previously described, Vohs found herself feeling sad after her daughter was diagnosed with cerebral palsy even though her daughter was doing fine, she was seemingly happy, they had a house to live, and so on. She discussed how notions of disability and “unbelonging” are in the air and we don’t even realize it. She offers an anecdote about the castles in Europe that have been standing for hundreds of years.

Centuries ago, these castles were built with small enclosed rooms used for making bread. Today, some of the castles and bread making rooms still exist. However, it is no longer necessary to add yeast to the bread dough. This is because after centuries of being used for bread making these rooms hold the yeast culture in the air and it leavens any dough that is made there. Vohs equates our ideas about disability and belonging with the yeast culture in the air, invisible, forgotten, yet still in existence. As an early intervention practitioner, I feel it is my responsibility to challenge some of those unseen, often unthought of negative yet existing ideas. Therefore, in the next chapter I will discuss how attempting to understanding parental shifting pictures may impact practice. I also provide a personal reflection on how the process of working within an interpretive framework had an impact on my professional belief system.

Chapter 6: The Imagine Wheel Implications for Practice

Chapter Purpose and Organization

By conversing with a small number of parents of preschool children with disabilities I came to believe that a continually shifting process of meaning making exists. These parental “shifting pictures,” which I have referred to as the kaleidoscopic world, seem to have implications for early intervention practitioners. Therefore, chapter six addresses the fifth and final guiding question of the study: What implications can be drawn from this theory for the practice of Early Childhood Special Education?

It is important to note that as each family moves through their kaleidic world it may or may not include the concepts I have found compelling. Whether or not parents move through these exact stages is perhaps irrelevant. However, these four concepts helped me to arrive at a deeper understanding of parental “shifting pictures” and the concept of the existence of a kaleidic world. I have come to believe that as parents move in, out, or through, their kaleidic worlds there are three overarching concepts that early intervention practitioners may want to bear in mind. Therefore, I will present a discussion including: one, how early intervention professionals may think about reframing the idea of “normal;” two, the importance of empathetic witnessing; and three, the importance of professional reflection. I offer the idea that empathetic witnessing and practitioner reflection may be considered as core concepts of early intervention. I will also discuss possible directions for pre-service teacher training. I also revisit the concept of belonging. I conclude the chapter and the dissertation with a reflection of my journey entitled “From Technical to Deliberative Practitioner.”

Reframing Normal

Although we individualize instruction, in my experience, progress not explicitly related to specific goals is typically not discussed. Parents I interviewed discussed their disappointment with professionals when their children's unique strengths weren't recognized. I started to wonder if we were doing parents a disservice by continually viewing disability through the lens of "normal?" This lens can often distort what "normal" relationships are for children with disabilities. Moreover, the idea of "normal" seems to change over time. As one mother commented to me, "normal is a dryer setting." It shouldn't be used to describe the multitude of ways in which people effectively live their lives.

Bogdan and Knoll (1995) have argued that in the field of special education disability is viewed as an objective thing that an individual has. Viewing disability within these parameters the disability becomes an "objective reality" (p. 10, Kalyanpur & Harry, 1999). However, others have argued that a disability is only seen as a disability when the area of delay is an area that is valued by society (Kalyanpur & Harry, 1999). In other words, a learning disability, such as dyslexia, is viewed as a disability because in our culture reading is viewed as a valuable skill. However, if a child with reading difficulties lived in an agrarian society, he would probably not be labeled as disabled. Furthermore, if a child is seen as a poor musician or artist, they are not viewed by the educational system as having a learning disability in the arts, just as a child who is not musically or artistically inclined.

Irving Kenneth Zola, who became disabled when he contracted polio and was then involved in a automobile accident all before he turned twenty, has studied the social and psychological aspects of illness and disability. He (1995) more eloquently discussed how viewing life through the lens of "normal" has an impact on those who are different:

Born for the most part into normal families, we are socialized into that world. The world of sickness is one we enter later, poorly prepared and with all the prejudices of the normal. The very vocabulary used to describe ourselves is borrowed from that society. We are de-formed, dis-eased, dis-abled, dis-ordered, ab-normal, and most telling of all, in-valid. (p. 206)

The labels we use and how we communicate information to families seem to have potentially far reaching effects.

Professional-parent communication has been examined in a systematic way regarding how members of the medical field communicate a child's diagnosis to a parent (McGaughlin, 2005). I feel this topic is relevant here because similar to the medical field we in special education often try to "fix" what is wrong, which may not be the most appropriate approach. Additionally, because we work with very young children we may be the first group of professionals that parents interact with on a regular basis. These early parent-professional relationships may set the tone for later parent-professional interactions. Therefore, understanding early communication patterns and perceptions seems pertinent.

Cunningham, Morgan, and McGucken (1984) studied how Down syndrome was reported to parents and they concluded that parents were often presented with a picture of a future filled with grief and struggle. The authors surmised that this picture ultimately inhibited the parents from coping and responding effectively to their child. McGaughlin (2005) asserts that this medical approach to diagnosis - something is wrong and needs to be corrected - signifies to parents that no hopeful future or quality of life is possible. He continues that poor communication during diagnosis may leave a legacy of suspicion and anger that influence future relationships between parents and professionals.

By continually focusing on "normal" skills we want the child to achieve, are we following the same path, and unwittingly sending the message to parents that something is

broken and needs to be fixed? One mother (Turnbull, Blue-Banning, Turbiville, Park, 1999) talks about her uneasiness with attempts to make her child “normal.”

I remember one developmental milestone that he never achieved – stacking three blocks. He had finally achieved stacking two blocks; the next milestone was stacking three. I modeled for him, prompted him, and finally held his hand while we did it together. Inevitably, when left to attempt it on his own, James would pick up the blocks and throw them. He found this hysterically funny. His early intervention teacher thought he was noncompliant. James obviously didn’t get the fact that his ticket to acceptance rested heavily on stacking those blocks (p. 164).

Another mother, Betty VanHoogmoed (1995) has discussed the first two years of her son’s life as negative. She stated, “It seemed every interaction involving our son emphasized only the things he was unable to do” (p. 20). She continued that the negative focus came from well-meaning professionals as well as family, friends and strangers made clear by questions such as “What is wrong with him? Is he doing this yet? Have you tried this?” One mother (Bruder, 2000) describes how she felt after another meeting discussing her son’s needs:

I signed it because I was told that services could not continue if I didn’t. I was concerned because I didn’t think it was doing anything for Cameron’s development. ... I also knew that I had a stack of old documents in which Cameron had not attained a single goal. I am starting to feel like a failure as a parent (p. 106).

What if as Vohs suggests (1993) disability is normal already? Other parents of children with disabilities have also suggested as such. Bob Dale, a father of a son with disabilities writes in the book, *Uncommon Fathers*:

It seems a contradiction to refer to a person who is deaf or blind or quadriplegic as perfect, but one has to assume that if the universe is indeed unfolding, as it should, then being deaf, blind, or quadriplegic is to be part of it. It is, therefore, as it should be (Dale, p. 5).

Maybe instead of continually stressing normal developmental milestones and specific skill related goals and objectives we should focus on ways parents can make their lives and their children’s lives the best they can be. It seems that when we evaluate children

with disabilities the expectation is that they should function independently, however, we all rely on supports in our lives such as technology, tools, and other people (Hammel, 2003).

I realize that many types of assessments are available (Losardo & Notari-Syverson, 2001) that attempt to focus on the whole child such as play-based assessment (Linder, 1990) and authentic assessment (Bagnato, Neisworth & Munson, 1997). However, practitioners typically use a standardized test such as the Battelle (Newborg et al., 1994) especially for purposes of qualifying a child for services and measuring progress at the annual IEP meetings. These scores are written up on the proper paperwork and reported to parents. Others concur with this observation (Chambers & Childre, 2005; Keyes & Owens-Johnson, 2003).

During IEP meetings, families are often assigned the role of submissive receivers of information, and the information that is shared is often deficit-focused (Chambers & Childre, 2005). Another parent who participated in Bruder's (2000) study commented "How come the reports were so negative, and they didn't say anything positive about Michael?" (p.105). Our professional decisions regarding what is pertinent to include in evaluation reports to families, and how to talk to families about their lives during both formal and informal meetings may have a larger impact on a family's functioning and feelings than we initially imagined. I think that often practitioners participate in meetings with families in a specific way due to time constraints, paperwork issues, or lack of knowledge concerning how each family views progress and improvements in their own life. However, it may be time to revisit our standards.

In addition, instead of showing progress related solely to normal developmental milestones, it seems important that we also discuss positive things children have achieved in other areas of life. All of the stories that parents shared with me helped me to think about what

and how I communicate with families, and what may be the lingering effects of my words after my work with the child is finished. In sum, these parents helped me to consider what is normal? In contrast to the results from the Cunningham, Morgan, and McGucken study (1984), Levi and Rosenberg (2005) found that parents reported higher satisfaction during informational meetings with educational staff when the child's strengths were addressed, and when hope and optimism for the child were conveyed during the course of the meeting.

Reid, Epstein, Pastor and Ryser (2000) have called for the use of strengths based assessments to be examined when assessing children with learning disabilities and emotional behavioral delays. Others (Dunst, Trivette, & Deal, 1994) have also recognized the need for strength-based assessments. I would tend to disagree with the method in special education for strength-based assessment, as the approaches tend to be positivist by suggesting the use of strength-based tools. However, the underlying assumption of recognizing a child's strengths remains the same. I would also suggest that in order to understand the context of each family's views on child's strengths, and to learn what families hope for it is imperative that we listen to them.

The Importance of Becoming an Empathetic Witness

I interviewed families who had children between the ages of three and six. However, as early interventionists our first interactions with families, and our first chance to truly listen to what families want, often occur before a child goes to preschool at age three. Between the ages of birth and three early intervention services are typically provided in the child's home, where each therapist often has uninterrupted time each week to work with the child and get to know the family on a fairly intimate basis.

Therefore, I find it necessary to focus for a moment on early intervention practitioners who begin working with children before they attend preschool. Focusing solely on parents, such as helping them to understand a diagnosis or listening to parents as they talk or cry, is not typically considered part of the job unless practitioners were also directly serving the child while they listen to the parent. Most early intervention practitioners I have known realize that supporting parents in this manner is often unrealistic, as it is difficult if not impossible to accurately listen or carry on a serious conversation while working with a toddler with a disability.

In May of 2005, the Council for Exceptional Children (CEC) and the Division of Early Childhood (DEC) published ten standards related to the knowledge and skill base for beginning early intervention practitioners to be utilized when working with children birth to eight years of age (www.cec.sped.org). Standard ten relates to collaboration and is comprised of ten skills. The standards discuss collaboration with families, other caregivers and agencies in order to support the child's development and learning; to support the families' choices in development of goals and intervention strategies; to assist the family in planning for transition.

Additionally, the Pennsylvania Department of Education's governing code (www.dpw.org link to 55 PA Code 4226.55) defines special instruction as "activities that promote the acquisition of skills...curriculum that leads to achieving outcomes on the IFSP, and providing the family with information, skills and support related to enhancing skill development of the infant or toddler with a disability." Skills are certainly worthwhile and necessary. However, perhaps by focusing on skills we are not providing support in other areas that family may need. By assuming that skill acquisition is of primary importance to all families that we

serve are we missing other essential aspects of social development? If we are not taught to truly listen to families how can we ever understand what supports they need?

Additionally, if one believes in the family-centered philosophy should we view listening carefully to families as an act of secondary importance while focusing on the child's skill development? This seems to be the antithesis of what we are supposed to be doing. I am not suggesting that practitioners take on the role of social worker or therapist. I believe that skill development is a valuable component of early intervention. However, for some families on some occasions, skill acquisition may not be what they want to focus on, and these shifting needs should be recognized and supported when possible.

Documenting direct service with a child and demonstrating progress on specific skills is certainly one way to view success, but I think the field should begin to acknowledge others, and by listening to families, and empathetically witnessing their stories we may be able to begin to slowly shift the paradigm. I think most EI practitioners sense the innate importance of supporting parents as they struggle with issues and do their best to lend their knowledge, support and understanding in ways that are family-centered. However, if EI teachers are not taught how to listen, and if listening is not typically addressed at in-service meetings and workshops, how should we begin to view its importance?

Furthermore, once children reach preschool age and services are provided in a school setting, parents have even less communication and time with teachers. In order to provide time for teachers to listen to parents once children are attending school, perhaps we should look to Headstart programs, which require two home visits from a teacher for each child during the school year. By providing a space where our only job is to listen to what parents would like to

tell us, we may be better able to provide services and supports that families would deem as family-centered.

As Barnard (1995) has suggested by empathetically listening and responding to others as they talk about their lives reassures people that their stories are important to us. It reaffirms their hopes and aspirations for the future. This leads to the importance of Kleinman's concept (1988) of empathetic witnessing. Kleinman, who worked with people who were chronically ill, defines empathetic witnessing as "the commitment to be with the sick person and to facilitate his or her building of a new narrative that will make sense of and give value to the experience" (p. 54). By allowing others to talk about their experiences related to illness and disability, we allow people our support in a reformulation of self and/or the sharing in helping to form potential future possibilities.

Barnard (1995) further explains, that by listening to the stories of others we can help to "mitigate their anxiety in uncertain times before they begin to gain confidence, coherence and direction (p. 54)" once again. I think that by stressing the importance of empathetic witnessing as a core concept of early intervention we can begin to empower families and take strides toward a truly family-centered model of early intervention practice. If we begin to take time to listen, *and only listen*, to parents we may be able to support them and their children's social relationships, among other needs, in a more pertinent and appropriate manner. Kearney (2001) has also suggested that by listening closely and attentively to what families have to say we may be able to foster insight and empathy into misunderstood issues, which may lead to the ability to offer support in more insightful ways.

Additionally, parents seem to look to professionals for emotional support as well as practical help and information (Featherstone, 1980), and if we do not take the time to understand

families' values we run the risk of leaving parents dissatisfied with our expertise and services (Rolland, 1993). Listening and "understanding the values, priorities and hopes of families... appears to be fundamental in providing services in ways that maximize the likelihood of success of intervention" (King, et al., 2006, p. 365).

Interestingly, during the course of this study, because I was able to concentrate on listening to parents in depth, some topics came up that were surprising to me. One in particular was the perceived impact of The Health Insurance Portability and Accountability Act (HIPAA) on friendships. HIPAA was passed to ensure that an individual's health information is kept confidential. However, according to three parents I interviewed some teachers believe they are no longer to share information about students with fellow students because of HIPAA. Therefore, on the occasion that a child plays with another child at school on a regular basis, teachers seem to be unwilling or unable to share names and other identifying information with parents so that parents can follow up on play dates or get-togethers outside of school. Particularly in light of the fact that both mothers (Bauminger & Shulman, 2003; Kolb & Hanley-Maxwell, 2003; Overton & Rausch, 2002) and researchers (Danko & Buysse, 2002) have expressed the need for sharing information about school relationships in order to support home relationships this seems to be a disturbing side effect of the usage of HIPAA. It may be that teacher and or families are confusing FERPA (The Family Educational Rights and Privacy Act) with HIPAA, or that teachers and/or families are misinterpreting the law. In any case, the examination of teachers' understanding of the law and the effect of their understanding and interpretation on the friendships of children with disabilities may be a potential area for future research.

The Importance of Becoming a Reflective Practitioner

In addition to carefully and respectfully attending to what others have to say in the form of empathetic witnessing, it is also important to take time to reflect on one's own practice as some scholars have previously discussed (Bowman, Donovan & Burns, 2000; Hatton & Smith, 1995; Noddings, 2003; Schon, 1987; Wesley & Buysse, 2001). Through this process of qualitative inquiry, I came not only to understand the complexities of parental meanings of social relationships, but I also came to understand many things about my practice and myself. Through memoing and engaging in discourse with others I had the luxury of reflecting on my practice in a much deeper manner than I had ever done during the course of a typical work week or month.

Although one definition of reflection has not been agreed upon, the term is generally used to refer to a continuing practice of critically examining one's own past and current actions in order to make decisions about one's future actions (Wesley & Buysse, 2001). Wesley and Buysse outline three key features of utilizing reflection within the field of early intervention. First, they claim that for a practitioner to engage in reflective practices he or she should "record events and reactions to events in everyday practice" (p. 116). They posit that documenting beliefs and perceptions in order to reconstruct and understand experience is at the heart of reflective practice. Second, they encourage the reflective practitioner to participate in conversations with other practitioners; and third to collaborate with researchers, other practitioners and family members "as partners in research" (p. 116). Wesley and Buysse discussed that by engaging in a variety of discourses about our own practice with a variety of people we stand to gain multiple viewpoints on our experiences.

Furthermore, they state that by participating in a variety of collaborative efforts, the act of reflection moves beyond a personal exercise and may influence larger early intervention issues

including discussion of professional roles, values and other existing concepts in a larger “social and political context” (p. 116). Wesley and Buysse (2001) draw on the work of both Schon (1983; 1987; 1991) and Senge (1990; 1994; 1999) to explain that the underlying purpose of engaging in reflection is to introduce ideas as a means to “stimulate individual and collective thinking about new ways to approach our efforts to build the knowledge base and improve practice” (p. 117).

In addition, Bruder (2000) and Wesley and Buysse (2001) have called for the field of early intervention to create “learning communities” or “communities of practice.” These communities of practice can function by providing opportunities for reflection and collaboration, with the purpose of developing common tools and understandings. Additionally, collaborative efforts may be made richer, they posit, by including people of diverse educational levels and background, and by recognizing the value of both families and practitioners as “co-constructors of knowledge” (p. 120). By building bridges through communities of practice that include reflection and collaboration we may be able to lessen the separation between research and practice, and to help make teaching a less isolating experience.

Drawing from my own experience, I have always enjoyed the “down-time” during in-service workshops and day-to-day teaching, when I have had the opportunity to simply sit and talk with other professionals. I have often learned of solutions to problems I had been struggling with on my own, suddenly made easier when others were involved in the experience. Furthermore, in more formal settings such as team-teaching, embedded therapy sessions, or participation in a trans-disciplinary clinical setting, I have without a doubt learned the most about my practice and myself.

Perhaps through reflection we can move toward a more “kaleidic” view of practice, which recognizes the importance of skills and also the importance context when listening to families in order to understand more intuitive ideas such as belonging. There is support in the literature for this type of practitioner, although not named as such. Fox, Vaughn, Wyatt and Dunlap (2002) have stated that families have “treasured and felt supported” by professionals who had “established caring and intimate relationships, rather than focusing on who had assisted their child in making gains or achieving outcomes” (p. 448).

Special education teacher and professor Lous Heshusius (1996) has commented that striving for understanding may eventually lead to the elucidation of questions of humanity. Yet, formal discussion about reflection and time set aside to participate in reflective and dialogic activities have been few and far between in any of my formal preparation to be a teacher. Therefore, if we are to consider empathetic witnessing and reflection as core concepts of early intervention, we must also consider pre-service teacher training.

Pre-service Teacher Training

Training specific to early intervention has been called for before (Bruder, 2000; Pretis, 2006; Wesley & Buysse, 2001). However many states do not require specific training for early childhood special education and some states include working with young elementary students, often up to fourth grade, in early childhood special education training (www.ecs.org). Given the unique challenges that early intervention practitioners face it seems that this idea needs to be addressed once again.

Pretis (2006) has noted that currently many skills taught to early intervention professionals are technical in nature. Kalyanpur and Harry (1999) have noted that this type of teacher preparation “appears to have two unfortunate consequences” (p. 9), the first related to

teachers, and the second to students. First, by completing training of this nature, teachers are often left with one choice - to operate as technicians. Teachers learn the pedagogy of educational areas such as “teaching social skills” and are taught strategies to help students achieve these student objectives. Skrtic (1991) has posited that the ramifications of this process have caused special educators to focus on the efficacy of “models, practices and tools, but not on its assumptions, theories, and metatheories” (p. 55). Second, in contrast to students who have been exposed or whose families follow mainstream understandings and assumptions, students who belong to a minority group, may not understand or operate under those same assumptions, and are often viewed as needing to be taught the strategies explicitly. Kalyanpur and Harry (1999) have posited this may be part of the cause for minority over-representation in special education.

In addition to addressing technical skills, Prentis (2006) has also discussed the variety of skills that early intervention professionals should have in order to be effective and they include: the ability to work in and with different familial systems such as parents, grandparents, siblings, and other significant caregivers; the ability to focus on child development; the ability to work with families of different values systems, different cultures, from socially disadvantaged backgrounds, or families that do not speak English; the ability to work in inclusive settings with other children and other professionals; the ability to work on teams with other professionals; the ability to generalize (by providing basic information) and specialize (by providing information unique to families); the ability to work in a variety of settings that include schools, homes, clinical settings, and daycares.

Wesley and Buysse (2001) have also listed the variety of roles taken on by early intervention practitioners such as diagnostician, curriculum designer, intervention provider,

community resource coordinator, services manager, materials broker, childcare consultant, inclusion marketer, community planner, program evaluator, and adult educator. Prentis (2006) also shares that competent practitioners must also have “personal competencies” (p. 43). He states that the ability to form attachments with families, and to be a part of the family also has an impact on service delivery. Guralnick (2005) has commented that given the complexity of the job, it is no wonder that working in early childhood special education can easily overcome even the most committed professionals.

Given that on a weekly basis and sometimes more often early intervention practitioners have to deal with an array of issues, it seems prudent to include some type of minimal training in counseling techniques such as listening skills, supporting a family through the time of diagnosis, and learning when it is appropriate to refer a family to a social worker for more intensive therapy needs. Additionally, learning about the importance of personal reflection and helping administrators and practitioners brain storm ways to use reflection in their daily practice may be welcome additions to the training we already receive on writing IEP’s, behavior modification, and strategies to use to teach skills. Utilizing formal reflective pieces may also provide a means to begin to examine the underlying assumptions and “culture” of special education, and to help in determining what is useful about the culture and what needs to be examined in greater depth.

In order to address some of these needs it may be helpful for teacher preparation programs to prepare future teachers to participate in what Wesley and Buysse (2001) have called professional communities of practice. Future researchers examining social relationships or parenting a child with a disability may want to concentrate on what belonging means to parents, and how parents envision their children belonging to our modern day society. These notions of

community and belonging seem to bring us full circle. Vohs entitled her 1993 article *On Belonging* and in deference to her I conclude my dissertation with a section of the same title.

On Belonging

As early educators we have much knowledge about what is appropriate and what services will most likely lead to the learning of new skill sets for each child we teach. We attempt to provide structured learning environments where goals can be met, but I think many parents are looking for an environment that provides much more than can be captured by the IEP. In the words of one mother (Lasalle, 2003, p. 59) who was looking for a preschool program for her young son with Asperger's syndrome:

Is this a kind place? Will you help my son make a friend?
Will you teach him to climb the jungle gym and play Cowboys
and Indians? Will you help him to not be afraid...? Will you
make sure other kids invite him to their birthday parties? ...

This affecting passage seems to summarize some of what we are missing.

Although we give family-centered practices much thought and discussion, family-centered practices are often approached through the lens of special education, and we may not even realize we are doing so. Families are offered certain services and approaches to learning and evaluation but the concepts have been pre-determined in large part by the early intervention system. I think part of what drew me to this study was an intuitive sense that social relationships could not be taught, and yet that is how they are often approached by the special education system. I have struggled with how to support families in their quest for social inclusion for the better part of my educational career. Social inclusion is something that cannot be broken down in discrete steps and assessed by the achievement of social objectives and goals. It is a moral issue that asks the question: Does everyone have the right to belong? Perhaps some future

researcher would be wise to ask parents of children with disabilities the question, “Where and how do you see your child belonging?”

Through constructive grounded theory methods I have come to understand that parents seem to be constantly adjusting to shifting pictures similar to those viewed through a kaleidoscope. By reframing how we view “normal” and by utilizing both empathetic witnessing and personal reflection I think we may be able to make the field of early childhood special education more family-centered than it currently is. In Chapter two I quoted Wesley and Buysse (2001) when they asked if the “field was ready to move to move toward accepting...interpretive knowledge of practitioners and families as part of a redefined knowledge base...” (p. 122). I think it is time to revisit their suggestion once again.

I hope that I have demonstrated that early childhood special education can indeed benefit from the types of understandings that can be gleaned from qualitative, interpretive study; and in some small way I hope I have contributed to the existing body of interpretive discourse in special education. For qualitative researchers, the intent of framing an issue is not necessarily to solve the issue, but to lead readers, who most likely include practitioners and other researchers, to envision and interpret a variety of solutions that may work for them (Charmaz, 2000). As Eisner (1993) stated, “We do research to understand” (p. 10). Furthermore, one of the strengths of grounded theory methodology is the ability of the researcher to construct a theory that is easily understandable to practitioners (Glaser & Strauss, 1967).

I envision that some of the meanings drawn from this study may lead some EI professionals to create programs and activities in a way that Meyer, Grenot-Scheyer, Schwandt and Harry (1998) called “doable in context” (p. 24). Many interventions have been developed under contrived circumstances that do not reflect the natural environment of the children and

families we serve. Plans that could easily be implemented by practitioners “would be adopted by a greater percentage of practitioners if it were obvious that the new strategy reflected the realities of practice rather than an ideal from research” (Meyer et al., p. 24).

For example, I have come to think that we should place the idea of belonging at the center of much of what we do. During the course of interviewing I began to understand that what I thought was difficult or sad about having a disability was not always what families viewed as difficult or sad. Although helping a child to master specific social skills is clearly important, I think it may be equally important to help parents smooth the way for their children to participate in other community activities.

Isn't it possible that instead of focusing the majority of our time on the teaching of “normal” social skills we may be more effective in the life of a child if we also talked to community leaders, helped to adapt programs so children in our care could participate, and put ourselves in the role of advocate in order to release parents from part of that burden? It seems to me that much of our job should be helping families to smooth the path toward belonging as much as we are able. If we follow that path, we may not be able to clearly measure and document all of our successes and failures. However, I feel strongly that it is a path worth exploring.

I would like to share some thoughts from Richard B. Steele (2000) who has written about parenting his daughter Sarah. Sarah is a teenage girl with serious medical issues. She has a disease called Fibrodysplasia Ossificans Progressiva (FOP), which causes her body to grow a second skeleton that is often in competition with her primary skeleton. This second skeleton grows where bones do not belong, protruding out from normal bones, crossing joints and penetrating her skin from the inside out. Gradually this second skeleton causes extreme rigidity turning the human body into a living statue. Additionally, Sarah was also born with a benign

brain tumor that was causing her to have vision loss, and would have eventually led to blindness had it not been removed. The tumor was removed when Sarah was eight years old, but her pituitary gland also had to be removed leaving her with endocrine deficiencies and a form of diabetes.

Steele relates how some days his life seems to be a series of struggles, like attempting to push ten thousand pebbles up a steep hill while willingly adjusting to changes in Sarah's daily needs. Based on his personal experience, Steele poignantly discussed the apparent futility of caring for a child with severe disabilities, and how it is difficult to imagine how his daughter will ever become independent. He continued that parents must either learn to live with these emotions or deteriorate and possibly collapse under the weight of day-to-day concerns and responsibilities. Steele comes to believe that one must "construe your misfortunes as opportunities, convert your fate into destiny, and search out what might be called the 'surplus of meaning' implicit in every calamity" (p. 171).

Steele shares that the meanings he has garnered from his experiences include the idea that human flourishing is possible in many realms. He is more open and receptive to the kindness of others, and has reframed his question of apparent futility. Why, he ponders, must labor yield results? Our society's need to observe material and measurable results sends us on furious quests to achieve more and more at a better and faster pace. And yet this quest seems to leave us more exhausted, more frustrated and less satiated than ever before, pushing us into a "frantic state of perpetual dissatisfaction." Steele posits that often performing an act with only intrinsic worth is simply the right thing to do, and will leave us feeling emotionally better and stronger for performing it. As Richard Wilbur (1987) wrote in the poem offered in the beginning of this dissertation, "this kaleidoscope, can, in that connection, give exercise in hope.

From Technical to Deliberative Practitioner

I would like to bring this dissertation to a close by offering my personal thoughts on my shift from a technical to a deliberative practitioner. As I have discussed throughout this dissertation, particularly in Chapter Three, the act of engaging in interpretive research was challenging to me for a variety of reasons. However, looking back over the process I learned much about myself and my practice. I entered into this study assuming I would find “answers” to a specific question I had pertaining to the social relationships of preschool children with disabilities and I emerged, not unscathed, from the other side with more questions than answers. Although the dissertation process is near conclusion for me and the defense of my work is called “the final defense” I have come to view these steps as a beginning.

Personally, I have come to understand that any knowledge acquired through force is not learning at all. There have been many occasions throughout this dissertation process, and indeed my entire academic career that I have “learned” things not for myself but in order to please others, to get a good grade, to pass a course. Unfortunately for me, I can no longer consider much of it learning; in fact I barely remember half of the things I learned quite well at various points in time. Learning and knowledge as I now believe are socially constructed and so many of the ideas I encountered I never really learned, even though I more often than not retained enough to get the grade or pass the course. This saddens me for if I had been more open to ideas that differed from my own perhaps I would be a more enlightened person.

Additionally, I have come to realize that throughout my college and graduate school career I have been asked to think, truly think, on very few occasions. As a new university professor I am often discouraged by the inability of my undergraduate students to think for themselves, not recognizing in myself this very same flaw. The few courses I took where I was

asked to think in a different and more deliberative way than I was accustomed to left me feeling unbalanced, confused. What in the world is this professor asking of me? I would often wonder as I exited the classroom door. What kind of grade will I get? Even after being repeatedly reassured that the grade was not necessarily a large concern to the professor, I still was unable to let go of past conventions and open my mind totally to new and often interesting ideas. My concerns were often related to the end result and not to the process.

During the course of this dissertation process I have had the pleasure of reading some of the work done by Thomas M. Skrtic. In his book, *Behind Special Education: A Critical Analysis of Professional Culture and School Organization* (1991) I have come to understand a concept that I have been aware of for quite a long time, but never really understood. Although if you had asked me if I understood I would have answered “yes” without a moment’s hesitation. This idea relates to the knowledge that public schooling was born out of the mindset of the industrial revolution, where factories and assembly lines reigned supreme. Within an assembly line you can make or fix or change whatever you need to and turn out the results at the other end. With relation to my dissertation process, I was continually looking for precision and answers and strategies that would “fix” problems. I have come to discover that these goals are often unattainable.

Moreover, I have come to understand that without trust it is difficult to engage in a truly deliberative exchange of ideas which seems to me to be where the majority of learning takes place. I was lucky enough to be involved with a study group which met every three weeks and provided a forum for faculty and students to share ideas and written pieces. However, I often brought only surface ideas to the study group which prevented me from addressing issues and concerns related to the core of my study. I think this happened for a variety of reasons, the most

damaging one being my own personal baggage, which is probably similar to the baggage of other doctoral candidates. Here I was, close to reaching one of the defined pinnacles of academic success, and continually admitting I was unsure or floundering, or still learning was not an option for me. In retrospect, if I had been able and willing to share my concerns and trust in the people who were attempting to guide me, the process may have been easier, and I may have reached a few critical understandings much sooner. However, that idea is up for debate as Oscar Wilde once said, “the things that are worth learning can never be taught.”

I have walked down a path which has led me, sometimes willingly, sometimes kicking and screaming, and often accompanied by tears, to read authors I would never have considered as being related to my body of work and the original intent of my study; authors such as Thomas M. Skrtic, Lous Heshusius, Aristotle, William Ayers, Nel Noddings and Parker Palmer to name a few. However, reading those authors has provided me an alternate view point that has ultimately left me feeling more enriched than I could have ever originally imagined.

During the months leading up to my dissertation defense I found myself lucky enough to be teaching at a small private university, on my own as a professor for the first time. One of the courses I taught was a course on inclusion for general education majors and teachers who were already certified and working in the field. A few of the “students” had more years of classroom teaching experience than I did. Initially, this left me a bit unsettled, but as the semester wore on I became more comfortable in my own skin and a large part of that I believe was due to my new found comfort with the idea that it was quite acceptable to not have the answers. Additionally, through discussion and deliberation sometimes the questions and solutions that one arrives at are more interesting than the original assumptions and answers with which one began.

I still have much to learn as a teacher, but by allowing myself to be open to the ideas of others I think I am on my way to creating a deliberative community within my own classroom. At the end of the semester, one of the students I was initially a bit intimidated by came up to me and said, "I would like to thank you. I have to be honest, I was dreading coming back to college because I thought I was just going to hear all the same ideas about things to try in my classroom, half of which I have tried and they haven't worked. But you listened to us and you made me realize that there is not a magic trick to teaching kids with special needs; if I am willing I will be able to figure something out that will work. Good teaching is good teaching. You have made returning to the classroom as a student a pleasure." I sincerely thanked her and we said our goodbyes. I walked silently to my office, went inside and closed the door behind me. I sat in my chair behind my desk and allowed the first smile of accomplishment to slowly spread across my face.

And so, this journey from technical to deliberative practitioner has caused me to question myself, to question others, and to think. I have found that I often do not have the answers, and sometimes I am even unsure of the questions. But in accepting these ideas I have allowed myself a freedom to learn those things that are important to me as not only an early intervention practitioner, but as a teacher, a mother, a wife, a daughter, a person.

I would like to close with an excerpt from “Philosophy of Teaching” by John G. Wuchenich (2002):

The Why of Teaching so I’m told must be included here
 That is to say the Why of My and it should be sincere
 And so like many colleagues here, I do it for the name
 I do it for the money, and I love to play the game
 I do it for I understand to teach to learn-it’s all the same
 The first step in the progress of a nation or a man
 Is discontent said Oscar Wilde, Act One: The Lady’s Fan
 He also said the following, again I do agree
 Where ever fail “there is no sin except stupidity”
 One must learn to make decisions, for some this is quite new
 And know there’s moral value in everything you do
 And even though life not be fair, it matters not the pace
 But face the challenge offered, and stay the entire race
 For what counts is not the trophy, the money or the fame
 To learn to be the best you can, is reason for the game
 And so dear reader here’s the how and reason why I teach:
 To sow the seeds of discontent in every one I reach
 To shatter fortress stupid’s wall, tho sometimes be thrown back
 And suffer loss of soul and mind, Press ever the attack!
 Excelsior! Excelsior! I’m swung into the fray
 Excelsior! Excelsior! I bleed in shades of gray.
 With chalk, or word, or pencil blue, with humor, wit or fear
 I offer this and challenge that in hopes that ONE will hear.
 That what I have to offer is more than just a word,
 That here my ark of covenant transcends Camus’ absurd!
 I still hope to reach the proper mix of chip and dip...and ink
 That irritates or tempts our minds, to question all to THINK.

Appendix A. Letter to Parents with whom I had a previous Relationship

Dear Jane and John Doe,

I am writing to re-introduce myself to you and to invite you to participate in a research study. My name is Susan W. Parker, and I worked with your child and family as a developmental therapist before your child turned three. I am also a doctoral student at the University of Pittsburgh.

The aim of this study is to explore how parents think about the social relationships of their children. As you know, parental input is greatly valued in any early intervention program, which is why you, as a parent, are being asked to provide some insights into your child's social life. It is hoped that the information gathered from this study may help to inform early intervention practitioners and administrators about a variety of topics such as: service delivery, support services, and how IEP's can be written and implemented in order to best support children's relationships.

If you decide to participate in this study, it would involve agreeing to be interviewed by me. This interview would last approximately 90 minutes and would take place at a mutually agreed upon time and location. I would be asking questions about your views on social relationships and friendships for your child. In addition, you may be contacted for a brief follow-up interview to clarify any issues or statements if necessary. The interviews will be tape-recorded in order to have a record of each conversation. However, all names and any other identifying information will be kept confidential.

Your decision to participate in this study is totally voluntary. There are no risks and no benefits to you by agreeing to participate in this study. You have the right to withdraw from the study at any time. If you are interested in participating please print your name and number below, and return the bottom portion in the self addressed stamped envelope I have provided. I will then contact you to set up an interview. Please feel free to contact me with any questions. Thank you so much for your time.

Sincerely,

Susan W. Parker, M.Ed.

codyprkr@cs.com

412-600-8156

_____ Yes, I am interested in participating in the research study that will explore what parents think about their children's social relationships.

Please Print Name: _____

Phone: _____

Appendix B. Letter to Early Intervention Classroom Teachers

May 10, 2006

Dear EI Teacher,

My name is Susan W. Parker and the purpose of this letter is to ask you for your help. I am also an EI teacher and I have worked in many settings: the classroom, in homes, in a clinical setting at Children's Hospital's UCLID clinic, as an intern at the CDU, and as a preschool service coordinator for the Chester County IU near Philadelphia. However, I am currently working on my Ph.D. in Special Education at the University of Pittsburgh. As part of my dissertation process I am required to complete a research study. I plan to complete an interpretative grounded theory study on the meanings parents make of their children's social relationships.

In order to accomplish this I need to talk to parents! I am asking you to pass out the 12 enclosed letters to parents you think may be willing and interested to talk to me for about an hour to an hour and a half about their children. I am attempting to get a cross section of parents: single, married, suburban, urban, etc., who have preschool children with any type of disability. I will interview them at home or any mutually agreed location. If they are interested they can contact me directly, directions for them are included in their letters.

If you have any questions about distributing the letters or about the study please feel free to contact me at my cell number (412) 600-8156, my home number (412) 531-5658, or through email codyprkr@cs.com. Thank you so much for your time!

Sincerely,
Susan W. Parker, M.Ed.

Appendix C. Letter to Parents with whom I did not have a previous Relationship

Dear Parents,

I am writing to introduce myself and to invite you to participate in a research study. My name is Susan Parker, and I am a doctoral student at the University of Pittsburgh. I have also worked in the early intervention field for almost 20 years.

The aim of this study is to explore how parents think about the social relationships of their children. As you know, parental input is greatly valued in any early intervention program, which is why you, as a parent, are being asked to provide some insights into your child's social life. It is hoped that the information gathered from this study may help to inform early intervention practitioners and administrators about a variety of topics such as: service delivery, support services, and how IEP's can be written and implemented in order to best support children's relationships.

If you decide to participate in this study, it would involve agreeing to be interviewed by me. This interview would last approximately 90 minutes and would take place at a mutually agreed upon time and location. I would be asking questions about your views on social relationships and friendships for your child. In addition, you may be contacted for a brief follow-up interview to clarify any issues or statements if necessary. The interviews will be tape-recorded in order to have a record of each conversation. However, all names and any other identifying information will be kept confidential.

Your decision to participate in this study is totally voluntary. There are no risks and no benefits to you by agreeing to participate in this study. You have the right to withdraw from the study at any time. If you are interested in participating please print your name and number below, and return the bottom portion in the self addressed stamped envelope I have provided. I will then contact you to set up an interview. Please feel free to contact me with any questions. Thank you so much for your time.

Sincerely,

Susan W. Parker, M.Ed.

codyprkr@cs.com

412-600-8156

_____ Yes, I am interested in participating in the research study that will explore what parents think about their children's social relationships.

Please Print Name: _____

Phone: _____

Appendix D. Background of the Study – Participating Families

| Family Members | Child | Age | Diagnosis | School Placement | Severity of Disability | Other Siblings? |
|--------------------------|----------|-----------------|------------------------------|---|------------------------|---------------------------|
| Lara & Dan (Mo & Fa) | Paul | 4 $\frac{3}{4}$ | PDD-NOS | Easter Seals T to Typical PS in Fall of 2006 with TSS | Moderate | Yes, 6 yr. old brother |
| Annie (Mo) | Clay | 3 | Autism | EI classroom, 3 days/week Typical PS 2/days week | Moderate to Severe | No |
| | Nate | 5 | DevDelay | K | Mild | |
| Bianca (Mo) | Matt | 3 $\frac{1}{2}$ | PDD-NOS | EI classroom | Moderate to Severe | Yes, 6 yr. old sister |
| Lynda & Lois (Mo & GRMo) | Bruce | 4 $\frac{1}{2}$ | Hemimega-encephaly | School for the Blind | Severe | Yes, twin sister |
| Mary Kate (Mo) | Susan | 3 $\frac{3}{4}$ | Autism | Typical PS with TSS | Mild to Moderate | Yes, 6 yr. old brother |
| Dawn (Mo) | Bradley | 3 | DevDelay | EI classroom | Mild | No |
| | Johnny | 6 | Asperger's | K | Moderate | |
| Bonnie (Mo) | Caden | 3 | PDD-NOS | Private EI classroom | Moderate | Yes, 5 yr. old sister |
| Carolyn (Mo) | Jennifer | 5 $\frac{3}{4}$ | DevDelay | EI classroom T to K in Fall of 2006 SPL & OT supports | Mild | Yes, 7 yr. old sister |
| Peggy (Mo) | Nicholas | 3 | Had been labeled as DevDelay | Was in EI classroom; tested out; now in daycare | Mild | Yes, 5 yr. old sister |

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